

how?
what?



set5et50c

This book has been written for young people aged 12-15

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findingout

medstuff

heartstuff

lifestuff

beyondcancer

handystuff

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introduction
introduction
introduction
introduction
introduction
introduction
introduction



So you have been diagnosed with cancer.

Now What...?

Whether you have just been diagnosed, are already having treatment or have completed most of your treatment, there are probably so many things running through your head all at the same time – questions, feelings, new thoughts – that it's hard to know where you are, let alone what's going to happen or what you might do.

Well, this book is designed to help you get a handle on some of what is going on and give you some tips and encouragement for dealing with the massive challenges that your cancer diagnosis has thrown at you.

Cancer is the last thing that anyone would invite into their lives. But now that it's here, having the right kind of help and information can make a big difference in dealing with it.

Introduction

This is not a “book” to be read from beginning to end but rather something for you to dip into when you need it. Depending on what stage you are at in your cancer experience, your need for information will probably change. Different sections of this book will be relevant for you at different times. We recommend that you just read the bits that are important to you now, then put it away to refer to at another time.

This book is also not supposed to be a substitute for talking to your doctor. If you are confused or worried about anything at all, you should always bring it up with your medical team. There is a lot of support for you out there if you ask.

We’ve had a lot of input from other young people who have shared the same stuff – so it is designed for real life and recognises that even though you are living with cancer, you are still a young person and have all sorts of other things going on in your life.

We hope that you find information in here that helps you get your head around the weird and scary world that you’ve just landed in.

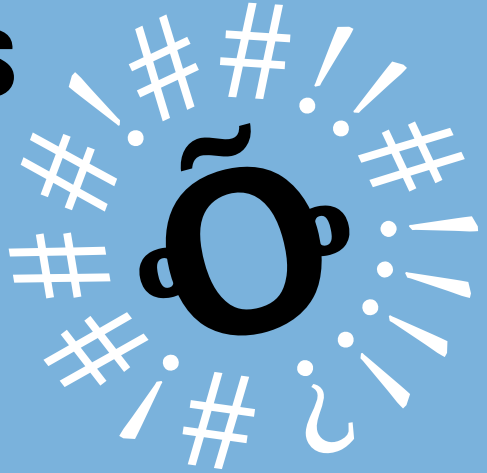


Top Tips

Don't let others
keep on giving
you bad advice

Hearing the news

WHAT the?



If you are reading this section, chances are you have just heard “The News” and your whole world has been turned upside down.

Everyone reacts to a diagnosis in their own unique way... but it's never, ever easy. You may still feel completely overwhelmed and be unable to focus on much at all. It's probably pretty hard to even accept that all this is really happening.

The truth is that right now, whatever you're feeling is fine. You may be numb, confused, angry or scared. You might feel like blaming anyone and everyone – from your parents to your doctors to the random on the street. You might be asking “why me?” – because it really is just so unfair.

There is no right or wrong way to deal with this massive bombshell that has just been dropped. If it takes a while to come to terms with things – that's totally normal!

How the doctors arrived at that diagnosis may be a bit of a blur, but it probably involved lots of tests, scans and appointments as well as a lot of waiting for results.

But now, things may start to move very quickly. There will be lots of new words and terms thrown around and it will seem like there are lots of decisions to make.



Remember:

**You do not have to go through this alone!
There is lots of support available and
people to help you get through this.**

Take a breath

(things to focus on)

Been holding your breath since you heard the dreaded C-word? As hard as it might be to focus on anything, there are a few things that might help you get a better handle on the situation.

Many young people survive cancer

Discoveries of new and more effective ways of diagnosing and treating cancer are being made all the time, leading to improved survival rates.

Even though you may be completely freaked and probably feeling quite sick, remembering this may give you some hope during tough times.

There are others out there

While no-one will feel exactly the same way as you, there are lots of other young people out there who are living with cancer. It can help to know that others are experiencing similar things. See "Where to get help" for websites to connect with other young people.

It is not your fault

Cancer is caused by lots of things, many of which doctors don't even understand. But none of these have anything to do with anything you did, said or thought.

Knowledge is power

Having the right information can be a big help in dealing with your cancer. Learning about your particular cancer and its treatments can take some of the fear out of it.

Things imagined can often be worse than the reality. If you are wondering about anything at all, don't be afraid to ask. A doctor or nurse won't mind you asking as many questions as you like.

There is no right or wrong way to feel

Every person will react to the news and cope in their own way. Your thoughts and emotions can feel overwhelming, but they will come and go. Keeping your emotions hidden probably won't help, so try to be as open and honest about them as you can.

Hope

Hang on to hope. It doesn't matter how dark things may get, try and find something to be hopeful for. No-one can take that from you; never give it up.



So what is cancer *anyway?*

You may have been familiar with the word ‘cancer’ even before you were diagnosed. But knowing what it actually is is a different thing. There are so many stories about it and so much written about it, but not all of what you read in the mags and newspapers, read on the net or see on TV is correct (what a surprise that must be!).

Cancer is a disease of the cells. Our bodies are made up of billions of cells – they are basically like building blocks.

Normally, cells grow and divide to make more cells only when the body needs them.

This process helps to keep the body healthy, replace worn out cells and heal after an injury. However, sometimes this process doesn’t go according to plan and the cells can get out of control, producing new ones even when they aren’t needed. This behaviour by the cells can form a mass of tissue called a growth or a tumour.

Tumours can be benign (not cancerous) or malignant (cancerous).

Benign tumours can often be removed and don’t spread to other parts of the body.

Malignant tumours can also often be removed, but they can also invade and damage nearby tissues and spread to other organs in the body. The spread of cancer from one part of the body to another is called “metastasis”.

Some cancers, like leukaemia, do not form tumours but are diseases of the bone marrow and blood.

There are over 200 different types of cancer.

Some are more common in young people than adults, and some more so in men than women.

The most common cancers in young people are explained in “What cancer is that?”

GETTING THE LOW DOWN

answering the cancer FAQs

How do they know I have cancer?

Cancer is usually noticed by its symptoms – such as extreme exhaustion, headaches or blurry vision. But because some of the signs of cancer can easily be mistaken for other common illness (even a cold or flu), a trip to your regular doctor may not have confirmed a cancer diagnosis.

If you were unwell for a long time, your doctor probably suggested doing some extra tests; X-Rays, magnetic resonance imaging (MRI) scans or laboratory testing. You might be starting to get familiar with all that poking, prodding and scanning by now.

When they identified cancer cells, you would have had more tests to find out what type of cancer it is and how far it has developed or spread. After a lot of appointments and waiting for results, the doctors would have given you your diagnosis. Now that they know exactly what you're up against, they will start to make a plan to treat it.

How did I get cancer?

Cancer itself is quite common – about one in three people will have cancer in their lives. But cancer in young people is quite rare. Each year in Australia about 1100 young people aged 12-24 are diagnosed with cancer¹.

The causes of most cancers are unknown. It is not a disease that you can catch from another person and you can't give it to anyone else.

There's no point blaming yourself; nothing you did caused the cancer. You might worry that smoking, drinking or taking other drugs contributed to you getting cancer. While there is a link between these things and some cancers, it is very unlikely to be so in people your age.

In young people, cancer can just happen with no explanation.

Can they cure it?

While most young people do survive cancer, the reality is that sometimes cancer cannot be cured. There are many factors that affect what the outcome will be, including what type of cancer you have, where it is and how advanced it is.

This is not an easy thing to have to deal with (massive understatement!) and it's OK to be scared. Ask your doctor to be honest with you about the prognosis (expected outcome) of your cancer. It is important to get the right information and right support.

How long does cancer last?

Everyone is different and everyone's cancer is different. Some cancers may take three months to be treated, while other cancers may take three years. One cancer treatment may have bad side effects and other treatments may have none. This may seem really unfair, but it just depends on the type of cancer and the type of treatment.

The likely outcome of your particular cancer is called your "prognosis", which is completely different for every person. Talk to your doctor about what you should expect in your specific case.

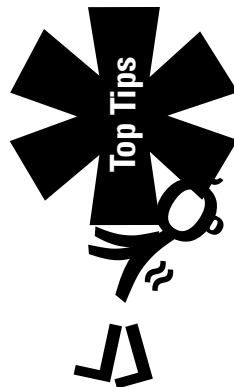
Who's in charge here?

Once you have been diagnosed with cancer, the doctors and other members of your treatment team will put a plan together of how they are going to treat your particular cancer.

Unfortunately, there will be some things that you have to do to get better, whether you like it or not. But there may also be some things that you can have a say in, such as when and where you receive your treatment – so don't be afraid to ask!

Your mum or dad will be involved in decisions about your care and treatment. You might be happy with this, but some of you may wish you had a bigger say in what is happening. For some tips on how to talk to your parents about being more involved in the decisions that affect you, see "Relationships – Parents".

don't be
afraid to ask
QUESTIONS



GETTING THE RIGHT INFORMATION

While you may not be afraid of the dark, being kept in the dark can really make you freak.

Not knowing what's going on can be stressful. You have a right to know what is happening to your body and having the correct information is an important way to help you cope with what's going on.

It can also give you a sense of control when everything else seems out of control.

Some people like to know every little detail, while others may only want to know things in a more general way. Whatever you choose is OK.

You might notice that how much and what you want to know may change over time.

The first thing you should do is ask lots of questions (or get your mum or dad to ask them for you)!



You wouldn't buy a new computer without asking questions...

**It's your right to understand
exactly what is happening to you.**

Here are some questions you may want to ask your doctor...

About the cancer:

- What kind of cancer do I have (in plain English please!)?
- What part of my body does it affect?
- What will it do to me?
- How do you know I have cancer?

About the Treatment:

- What's going to happen?
- What tests are you going to do?
- What kind of treatment will I have? Where can I find extra info about it?
- Will it be painful?
- Does the treatment have side-effects?
- How long does the treatment take?
- Will I have to go to hospital?
And if I do, for how long?
- Will I lose my hair?

- Will it change the way I look, feel or act?
- How will we know if the treatment is working?
- What happens if I don't have the treatment?
- What will happen if the treatment doesn't work?
- Have you ever treated someone with my cancer before? How many have you treated? How old were they?
- Is there anything special I should be doing, eating, reading etc?
- When you talk to my parents, will you include me and make sure I understand as well?

After Treatment:

- What will happen after I finish my treatment?
- Will the cancer come back?
- What about school and the rest of my life?



Argh! Information overload!!!

When you are feeling stressed, upset or scared, it can be hard to take in and understand all of the new information you are being told, especially at the beginning.

You will have heaps of appointments with different doctors and they will probably use quite a lot of medical lingo which might sound like a foreign language at the beginning (but you might be surprised by how much you know later on!).

Here are a few tips on how to get the right information and ways to remember it:

- Write your questions down before you go.
- Write the answers down, or take a voice recorder to listen again later (your mobile might be able do this).
- Ask people to repeat things if you don't get it the first time (or the second time or the hundredth time).
- Ask the doctor or the nurse to draw a picture or use a model (a plastic one, not a magazine one!).
- Take someone else with you – then you can check with each other and fill in the gaps if some info is missing.

You may
need to
remind
people
to talk in
PLAIN
ENGLISH,
not medical
language!





Without stating the obvious, the internet is a great source of information but as we all know it is also full of some pretty weird stuff. That's not always helpful when you are trying to get accurate and useful information.

Here are a few tips to make your Googling a bit more successful.

Always check the source of the information

Lots of the information on the net can be misleading or out of date. Look at where the information is coming from. Can you find contact information for the people behind the website? What is the purpose of the website – information or advertising? There are many reliable cancer organisations that have great information that is accurate and up to date.

Don't believe it all

If the claims in an article seem too good to be true, then they probably are.

Living with cancer can make us all very open to promises of cures and miracle treatments. Look who is behind the website you are on. If it starts with something like "I cured my own cancer in three weeks" or "The facts the medical profession won't tell you", chances are it is not a reliable site. People have all sorts of reasons for putting stuff up on the web.

It's a good idea to check out the claims being made on the internet with your parents, the doctors or nurses or a trusted web source. Most doctors are happy for you to print out something you have found on the internet and bring it to your appointment to ask their opinion on it.

What they don't tell you

Every treatment has risks and benefits. If the site doesn't mention both the good and bad bits it may not be telling the whole story. If you hear about a treatment from one website look for other evidence that backs it up on another website.

Make sure you are searching the right stuff

Each cancer is different and the treatments and outcomes for the same cancer can vary depending on things like the stage it's at and where it is in your body. Before you head off into cyberspace, make sure you have as much information about your own cancer as possible. (This could save you from freaking out when you don't need to.)

Use the web information as a starting point

Information found on the web can be a good way to start a conversation with your parents or your medical team. It may give you questions that you hadn't thought of and help you to get a better understanding of some things. You might also be able to connect with people in a similar situation who will understand what you are going through.

Check out the list of recommended websites in "Where to get help" or on our webpage www.nowwhat.org.au.

What **cancer** is that?



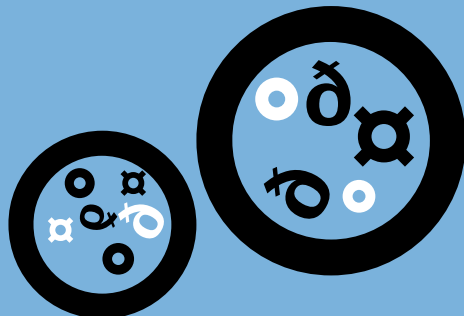
This chart lists the most common cancers in adolescents and young adults and the most common ways to treat them. If your cancer is not mentioned here then ask your medical team for more detailed information, or check out our website (www.nowwhat.org.au).

Type of cancer	Description	Treatment
Leukaemia	Leukaemia is cancer of the white blood cells (WBCs). Bone marrow and other blood forming organs produce abnormal numbers of white blood cells, stopping the production of normal blood cells.	
Acute Lymphoblastic Leukaemia (ALL)	ALL increases the number of WBCs called lymphocytes.	Treatment plans for ALL usually include chemotherapy and radiotherapy. This can be for up to 2 years. Some patients may also require a bone marrow transplant (BMT).
Acute Myeloid Leukaemia (AML)	AML increases the number of abnormal WBCs called myeloid cells.	Treatment plans for AML usually include 6 months of chemotherapy with 2-3 drugs in each course of treatment lasting 5-10 days. 4-5 courses of chemo are given on a monthly basis. Depending on the success of chemotherapy a BMT may be necessary.

Type of cancer	Description	Treatment
Lymphoma	Lymphoma is cancer of the lymphatic system, which is part of the immune system that protects the body against infection and disease.	
Hodgkin's Lymphoma	Cancer of the lymphatic system. Tumours affect the lymph nodes as lymphoma cells lodge in the system causing a lump, which you may find. These are normally close to the body's surface, such as in the armpit and neck.	Treatment depends on the stage of lymphoma. Most people need a combination of chemotherapy and radiotherapy.
Non-Hodgkin's Lymphoma (NHL)	Cancer of the lymphatic system that does not have the features of Hodgkin's disease. NHL affects the lymph nodes deeper inside the body. There are different types of NHL, the two main types being B-cell NHL and T-cell NHL. B-cell NHL usually affects the neck, head, throat and abdomen whereas T-cell affects the lymph nodes in the chest.	The most common treatment for NHL is chemotherapy and occasionally radiotherapy. There can be some short-term and long-term side effects from NHL treatment.

“ One thing I have learnt from this experience...
I can bounce back. ”

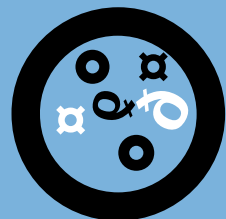
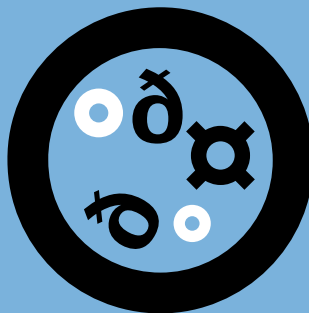
Type of cancer	Description	Treatment
CNS tumours	Cancers of the brain and spinal cord.	
Brain tumours	There are many different types of brain tumours. The most common tumours grow from glial cells which are the support cells in the brain.	Some brain tumours are more serious than others and require more aggressive therapy. Treatment usually involves surgery to remove the tumour, and then radiotherapy and possibly chemotherapy, depending on the outcome of the surgery.
Bone tumours	Cancer of the bones often starts in the ends of bones where the bone tissue forms as the young person grows.	
Osteosarcoma	Cancer that begins in the bone forming cells. It most commonly occurs in the arm and leg bones.	Treatment will depend on the size, position and stage of the tumour. Chemotherapy is usually given to shrink the tumour and then it is usually surgically removed. Sometimes this may involve amputation of the affected limb. Treatment usually lasts for 4-5 months.
Ewing's Sarcoma	A family of tumours found in the bone and soft tissues. It can develop anywhere in the body, but is usually found in the spine, hips, upper arm, long bones in the thigh or in the ribs	Treatment will depend on the size, position and stage of the tumour. Chemotherapy is usually given to shrink the tumour and then it is usually surgically removed. Sometimes this may involve amputation of the affected limb. Treatment usually lasts for 4-5 months.

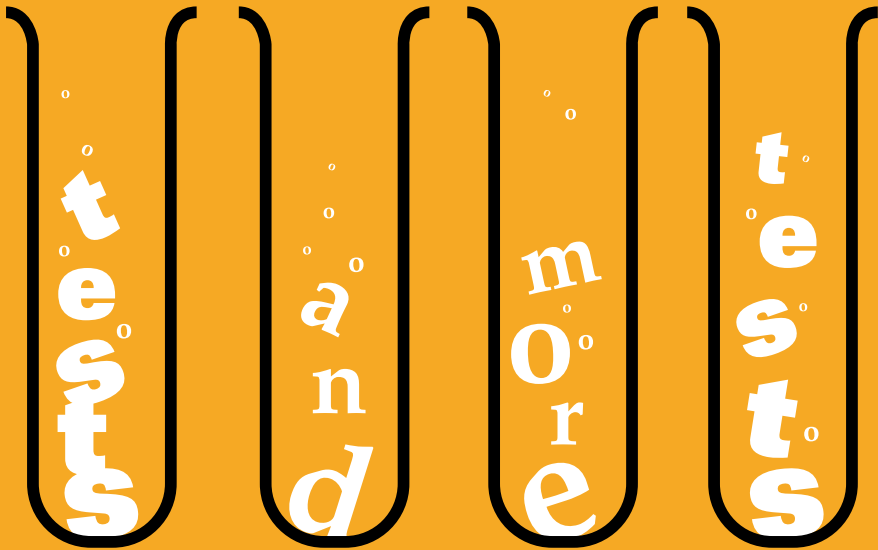


The most useful piece of information that I got was...
what was going to happen,
the side effects and
where the cancer was.

Type of cancer	Description	Treatment
Sarcomas	Sarcomas are cancers of the body's soft tissue – muscle, fat, and blood vessels.	
Rhabdomyosarcoma (RMS)	Develop from muscle and their surrounding tissues can affect any part of the body. They are commonly found in the head, neck, genital, urinary areas and the limbs.	There are 3 types of treatments depending on the size and stage of the sarcoma. Treatment mainly involves chemotherapy and radiotherapy, but can include surgery also. If RMS spreads beyond the primary site then high dose chemotherapy or a BMT may be given.
Fibrosarcoma	Cancer that develops in cells called fibrocytes that are usually found in the arms, legs or trunk.	Most people will need a combination of surgery, chemotherapy and radiotherapy treatments to get them back on track. The exact treatment plan will depend on your age, general health plus the stage and type of the cancer.

Type of cancer	Description	Treatment
Other cancers or tumours		
Germ Cell Tumours	Develop in the reproductive organs: testicles for boys and ovaries for girls. They can travel to other parts of the body including the chest, abdomen and brain. The most common germ cell tumours are testicular, sacral, chest and ovarian.	Most commonly involves surgery to remove the tumour then chemotherapy.
Melanoma	Melanoma starts from melanocytes, the cells in the skin that produce the skin pigment or colour. Melanoma grows quickly which means can spread to the lower layer of skin then into the body and other systems.	Melanomas are always removed by surgery. Radiotherapy may also be required depending on the stage of melanoma and whether it has spread to other organs.
Thyroid Cancer	Thyroid cancer is a cancer of the thyroid gland which is located in the neck. There are different types of thyroid cancer, categorised by growth rate, malignancy and type of cells affected.	Treatment may involve surgery, radiotherapy, chemotherapy and hormone therapy.





People who have cancer are often put through a whole heap of tests. Tests range from quick and routine to sometimes quite uncomfortable or painful.

It can be easier to deal with tests if you understand why they are being done and exactly what they will involve. Knowing what to expect can sometimes help you to feel less afraid.

But how much you want to know is up to you. If you read something here that you don't understand, are worried about, or want to know more about, bring it up with your doctors.

Here are some of the most common tests you may hear about (if you haven't already):

- Biopsy
- Bone Marrow Aspirate and Biopsy
- Lumbar Puncture or Spinal Tap
- Scan (MRI / CT / Bone Scans / Ultrasound / X-Ray)
- Electrocardiogram (ECG)
- Audiogram
- Pulmonary Function Tests
- Blood Tests

Biopsy

A biopsy is a surgical procedure used to determine whether a tumour is benign or cancerous. In this test, a small piece of tissue is removed from the tumour and examined under a microscope to check for the presence of cancer cells. The tissue is examined by a pathologist (someone who is expert in identifying the changes in body tissue caused by disease). This microscopic study of tissue confirms or rules out a diagnosis of cancer.

Bone Marrow Aspirate and Biopsy

Unfortunately, it's likely you'll have to have a few bone marrow biopsies during treatment if you've got cancer. It's an extremely important test which can accurately diagnose some types of cancer such as leukaemia, and help track the progress of your therapy (it looks at the body's ability to produce blood cells).

What is bone marrow?

The bone marrow is a type of soft tissue inside some of your larger bones, which produces red and white blood cells and platelets. By examining a small amount of your bone marrow, usually taken from your hip bone in an area called the iliac crest, your doctors can make important decisions about your care.

How does it all work?

First of all, you'll probably receive some medication to sedate you (put you to sleep). Some common drugs used are fentanyl and propofol (wonderful white stuff) and these will be administered by a doctor called an anaesthetist.

Then, you'll have to lie face-down on an examining table. A small blanket or towel may be placed under your hips to raise them. If you receive sedation medicine, you'll soon be off to sleep and you won't feel any of the procedure. Some people really like the feeling they get from propofol, as it makes all things very dreamy and relaxing, but it can make you feel a bit washed out for a few days afterwards.

After you're asleep, the biopsy area is cleansed and a local anaesthetic is injected to numb the skin. If you're not sedated, you will feel the prick of the needle and the local anaesthetic will sting at first. A biopsy needle is then inserted through your hip bone into your bone marrow and a small amount of bone marrow is pulled up into a syringe for testing. Again, if you're not asleep, you may feel some pressure and pain as the needle is pushed into your bone.

Once the bone marrow is extracted, a new needle will be placed in the same hole to get a small specimen of bone for further testing. The needle is pressed forward and rotated in both directions. This forces a tiny sample of bone into the needle. If a good sample is not taken, the doctor or nurse doing the procedure may need to try again. The needle is then removed and a pressure bandage (to stop bleeding) is applied.

A laboratory technician will examine the bone marrow and prepare a report for your doctor. This usually takes a few days.

Your back may be sore for a few days. Paracetamol (or Panadol) may help relieve the soreness. If you have lots of bone marrow biopsies throughout your treatment, your doctor or nurse will try to alternate sides to reduce scar tissue build up.

MRI (Magnetic Resonance Imaging) Scan

Most MRI scans take between 30 and 90 minutes. Your only job is to remain completely still because even slight movement can spoil the images. During the scan you will hear a variety of sounds such as humming and hammering. It may sound like the technician is hitting the side of the scanner with a large hammer. These sounds are normal. You may be given earplugs or stereo headphones to muffle the noise and in most MRI centres you can bring in an iPod, but don't be surprised if the music is drowned out by the noise.

You may be given 'contrast' solution during your MRI. This is a liquid that you either drink or is injected into one of your veins through an intravenous line (IV) and it helps the doctors and radiologists to see the different structures and blood vessels.

Other than maybe being a little uncomfortable (and loud!), an MRI is completely painless (except if you need an IV put in for the contrast) and you should have no side effects to worry about.

CT (Computerised Tomography) Scan

CT Scans (also known as CAT Scans) combine X-Rays and computers to produce very detailed cross sectional images of your body. Depending on what part of your body is to be scanned, you may be given 'contrast' solution to make things show up better on the scan.

The good thing about CTs is that they are quick, but you need to lie very still to get a good scan. After the scan is done, it can be computer reconstructed to show 3D images of the part of your body that was scanned.

Because the machine produces X-Rays, the technician is in a separate room near the computer, but can talk with you through an intercom. You will probably be alone in the room, unless you request that someone be with you. That person will need to wear a lead vest to protect them from the X-Rays.

Bone Scans

Bone scans can show abnormalities long before they show up in X-Rays, which is why the doctor may order one. The radioactive fluid is given through an IV and is absorbed by your bones as it travels through your body. You have to drink a lot of water or juice right after the fluid is injected to clear your body of radioactive material not absorbed by your bones.

The bone scan may take about an hour and again, you have to lie very still while the camera moves back and forth. You might be asked to change positions several times to get different images. Because no X-Rays are emitted, you can have someone stay in the treatment room with you.

The radioactive material or tracer concentrates in areas where there is a lot of activity, like normal growing bone or in bone tumours or bone infections. These areas will show up as "hot spots" on the scan.

X-Rays

X-Rays are a type of high-energy radiation used to take photographs of the body and identify anything that is out of place in relation to the bones and other structures.

Electrocardiogram (ECG)

Your heart generates electrical impulses causing it to beat or contract. The electrocardiogram (ECG) records these rhythms and electrical impulses through 10 electrodes that are placed on your chest, arms and legs. The test takes only 5-10 minutes and it's completely painless (yay!). It is usually done right in your hospital room or treatment room.

If you are taking certain chemotherapy drugs called anthracyclines, you will probably have an ECG prior to treatment and then again, periodically throughout your treatment. Because anthracyclines can cause damage to your heart muscle, your doctor will closely monitor your heart's function and adjust your treatment plan if necessary.

Audiogram

This test evaluates your hearing.

Some chemo drugs, such as cisplatin, can affect your hearing so you will need to have your hearing monitored. A baseline test (to see what your hearing is like normally) will be done prior to starting the drug and then periodically throughout your treatment. If you notice any change in your hearing, be sure to tell your medical team.

Pulmonary Function Test

A pulmonary function test measures how well your lungs work – specifically how much air they can hold and how effectively they function. It also looks at the forcefulness of your breathing. You may have a pulmonary function test because some chemotherapy drugs affect lung functioning.

**top
tips**

Let people
close to you know

**what is
going on**

– no need to keep it a secret

Blood Tests

Blood tests will become part of your life with cancer, so it can be helpful for you to understand what they're for. Various types of blood tests help diagnose cancer. Sometimes they are the first indicators of disease. Blood tests are also used to track the progression of your disease as well as help make decisions about your treatment.

Your doctor will often order a full blood count (FBC). Your blood "counts" will be closely tracked throughout treatment. You will become very familiar with these.

Three primary types of blood cells are formed in your bone marrow: red cells, white cells, and platelets. Plasma is the liquid part of your blood in which the other cells travel.

Certain kinds of cancer will affect the normal production of these cells. Some of the treatments you will receive, especially chemotherapy, will also affect your body's ability to produce blood cells.

Some of the types of cells in your blood that the doctors will monitor are:

- **Red blood cells (RBCs)** Your red blood cells are primarily responsible for carrying oxygen throughout your body.
- **Haemoglobin (Hgb or Hb)** Red cells contain haemoglobin, the molecule that carries oxygen and carbon dioxide in your blood throughout your body. If your haemoglobin is low, you'll be anaemic and may feel tired, be short of breath or look pale. You may be anaemic at diagnosis (partly why you may have felt unwell) as well as during treatment because of your bone marrow's inability to produce new red cells.
- **Haematocrit (Hct)** Haematocrit refers to the volume of red blood cells in your system. (This is also called packed cell volume – PCV). Your haematocrit count is the ratio of red cells to plasma (the liquid part of your blood). It is expressed as a percentage. As an example, if your haematocrit is 30 it means that 30% of the blood that was drawn is red cells; the remaining 70% is plasma. When you're on chemotherapy, your bone marrow's ability to make new red cells is decreased, so your haematocrit may go down. Because there is less oxygen in your body, you will feel tired and have little energy. If your haematocrit drops below about 18%, you may need a red blood transfusion. Your medical team will decide this for you.
- **White blood cells (WBCs)** Your white blood cells are responsible for fighting infection. Because cancer treatment affects your body's ability to produce white cells, your risk of infection becomes higher. There are a number of different WBCs in your blood.
 - **White Blood Cell Differential (DIFF)** The differential (or diff) refers to the distribution of different kinds of white cells in your blood. Each type of white cell will be listed as a percentage of the total. Neutrophils are the most important infection-fighting white cells. On your lab reports, the "differential" or "diff" will show the percentage of each type of white cell, all together equalling 100%. As an example:
 - **Segmented neutrophils (or segs) 49%**
 - **Band neutrophils (or bands) 10%**
 - **Basophils 1%**
 - **Eosinophils 1%**
 - **Lymphocytes 29%**
 - **Monocytes 10%**

Blood Tests

- **Absolute Neutrophil Count (ANC)** This count is a measure of your body's ability to fight infection. It is the percent of neutrophils (segs + bands) multiplied by the total white blood count (WBC). The magic number is an ANC of 1,000 or more. When your ANC is less than 1,000, you are at very high risk for infection.
- **Platelets (Pit)** Platelets are the cells in your blood necessary to stop bleeding. Because chemotherapy affects your bone marrow's ability to produce platelets, you will probably need platelet transfusions during your treatment. Signs of low platelet count include:
 - Bruising with no apparent cause
 - Any unusual bleeding (nosebleeds, bleeding gums, prolonged bleeding from a cut)
 - Petechiae (small red or purple spots on the skin)
- **Blood Cultures** If your ANC (Absolute Neutrophil Count) is less than 1,000 and you develop a fever of more than 38.0 C, there is a risk of serious bacterial infection. You may be hospitalised and started on IV antibiotics. To find out exactly what antibiotics to use, blood cultures might be drawn from your central line and sent to the lab. There, they can find out what type of bacteria grows in the culture medium (a substance that germs grow in) and choose the best antibiotic to kill it.

If there's ever a high chance of bacterial infection, extreme caution must be taken. Even if you feel perfectly fine, this precaution is necessary. Spending a few days in the hospital – just in case – is much better than taking a chance with a big infection.

See "When to worry" for more information on this.



Remember

You can continue
to live life

7R347M3N75 D3-COD3D ΔB3ϕΔW3MΔ2 D3-COD3D **TR3ATM3NT5 D3-COD3D** **TREATMENTS DE-CODED**

There are quite a few different treatments and therapies that are used to help get rid of cancer. They come in all different forms – from medication, to the use of X-Rays and light beams, to surgery.

What sort of treatment you get will depend on what cancer you have and whether the cancer has spread anywhere else in your body. You might have just one of the treatment types, or a combination of them.

Chemotherapy

Chemotherapy or ‘chemo’, is the most common form of cancer treatment. Chemo uses drugs, called cytotoxics, to kill or slow the growth of cancer cells. Unfortunately, while chemo drugs can stop cancer cells growing and multiplying, they also affect normal, healthy cells in the process. That’s why healthy fast-growing cells, such as the ones in your hair and inside your mouth, are damaged by chemo. Luckily, these cells reproduce quickly (so if you have lost your hair, it shouldn’t be too long until it grows back!).

Chemo drugs can be taken in a variety of ways. The most common method is using a central line (IV line) that has been put into a major vein in either the neck or the chest. Other methods include taking tablets, drinking liquids, having injections and using internal and external pumps.

Sometimes, the most effective way of killing cancer through chemo is by using a number of different drugs rather than relying on just one.

Each chemo period is called a cycle. After each cycle there is usually a rest period, where normal cells repair themselves and the body begins to regain its strength.

Chemo treatments can be given daily, weekly or monthly for several months to a year. This depends on the type of cancer you have and the treatment regime you are prescribed

Radiotherapy

Radiotherapy uses high energy X-Rays, gamma rays or electrons to kill cancer cells in a specific part of the body. It creates shifts in the body’s cells that destroy the cells’ ability to grow and divide. Radiotherapy only affects the cells and tissues within a specific area (unlike chemo, which affects the whole body). Normal, healthy cells are also better able to resist the radiation, so your body may recover from the effects of radiotherapy faster.

Radiotherapy can be used to treat cancer either on its own or in conjunction with chemo and surgery. The reason radiotherapy is often used is because it reaches areas of your body that surgery may not and it often has fewer side effects (although it still does have some).

There are two different types of radiotherapy – external beam radiotherapy (from outside the body) and internal radiotherapy (from inside the body). The type of radiotherapy used will depend on the type of cancer you have, its size, your general health status and what other treatments you may already have been given. There is also radiotherapy given to the whole body, called total body irradiation. This is often done before a stem cell or bone marrow transplant. Whether you have total body irradiation depends on your treatment plan.

Each radiotherapy treatment is called a fraction. Giving the treatment in separate daily fractions means that less damage is done to normal cells and there will be fewer side effects.

You can usually have radiotherapy as an outpatient and it is given once or twice a day for several weeks.

Surgery

Surgery involves a cancer being removed while you are under anaesthetic. Tumours are usually removed this way.

With solid tumours, it may be necessary to remove tissue around the cancer to make sure it's properly removed. Sometimes (unfortunately), the whole organ will need to be removed, or a body part amputated.

Surgery can also be used to perform a biopsy or insert an intravenous line. A surgical biopsy allows the doctor to remove a section of a tumour and have it analysed to find out more information.

Surgery is generally combined with chemotherapy and radiotherapy treatment for cancer.

Bone Marrow Transplant (BMT)

A BMT involves transfusing healthy bone marrow to replace bone marrow

destroyed by high doses of chemo. A transplant can either involve receiving your own cancer-free bone marrow that has been taken from you prior to treatment, or bone marrow from a compatible donor.

Conditioning treatment, which may involve high-dose chemo and total body irradiation, is first administered to kill the cancer cells. Then, the healthy bone marrow is given to you through an intravenous line.

Conditioning treatment will impact on your immune system and you will have a very high chance of getting an infection for a few weeks afterwards. To protect you against infection, you may be given antibiotics and blood transfusions and the hospital may restrict the number of visitors you are allowed to have. You might sleep in a special private room and have to wear gloves, masks and other protective clothing to protect you against infection if you leave your room. BMT can leave you feeling very sick and weak and unable to do much more than sleep and sit up. You might be in hospital for quite a long time, which can be very lonely and isolating.



Transplant

Stem cells are cells that are born in the bone marrow and later develop into red blood cells, white blood cells or platelets that circulate around the body. With a stem cell transplant, the cells are taken from your blood before chemo and then later returned after chemo (much like a BMT). Again, either your own stem cells or those from a donor can be used.

We don't have many stem cells circulating around in our blood, so a few days before the stem cells are taken an injection called G-CSF is given to increase their numbers. They are then collected by a procedure called leukopheresis, which filters the stem cells out of the blood through a machine over about 4 hours.

After you receive the high dose of chemo, the cells are then transfused back into the body (much like a blood transfusion). The cells will find their way back into the bone marrow eventually resulting in normal blood cell numbers.

Alternative Therapy

The treatments listed above are known as "conventional" cancer treatments and they are widely accepted and practised by the mainstream medical community. But there are also other kinds of cancer treatments, called "complementary" or "alternative" therapies.

Complementary therapies include things like counselling, art therapy, yoga, meditation and aromatherapy – all of which are believed to promote well-being. While they may not cure cancer, complementary therapies can certainly help in coping with treatment side effects and improve overall quality of life.

Alternative therapies are taken instead of medical therapies. Many of these are unproven. If this is something you are thinking about you should talk to your medical team. Most doctors are open to talking about alternative therapies and will not get angry or upset with you for asking about them.

Some complementary and alternative therapies can interact badly with other medicines, including chemo. Make sure you talk to your specialist or nurse before you take anything.

and

top tips Complementary therapy can be great, but always check with your doctor before using these treatments

OK, you now know about some of the treatments that you may be given. But what exactly is going to happen??

Try not to get too nervous about these things. If you are worried about anything at all, talk to your medical team. They can give you more information and help to make treatments as painless as possible.

Remember: It is OK to be scared.

When you are being treated for cancer, you may need chemotherapy, antibiotics, blood products, blood tests and sometimes nutrients (liquid food). All of these things are fed in through your veins. Intravenous (IV) lines are inserted so that all these treatments can be given more easily.

IV (Intravenous) Lines

Intravenous (IV) simply means “in a vein”. There are two main types of intravenous lines: **external** and **subcutaneous** (under the skin). Sometimes, you may have a smaller more temporary line inserted. You and your medical team will discuss which type is best for you.

Most of your drugs and fluids go in (“infused” in medical lingo) over a period of time through an IV line (tubing) that connects to an infusion pump. The pump keeps things flowing at a specific rate. Meds, fluids and blood for transfusions are usually hung on an IV pole to which the pump or pumps are connected.

GETTING HOOKED UP

THE INS AND OUTS OF RECEIVING TREATMENT

Central Lines

The most common type of external line is the central line, also known as the Hickman Line (named after the person who developed them). These lines make receiving IV medications, blood transfusions and blood tests easier. Everything you need is connected to your central line. Having a central line eliminates the need for repeated needles to start an IV line or to draw blood... so it's worth it!

How do they work?

All central lines work on the same general principle. A small tube or catheter is surgically implanted (under anaesthetic) and then fed into the superior vena cava – a major vein in the right part of your heart. The other end of the catheter is “tunnelled”

under your skin for a short distance, where it exits through another small incision at a spot near your breastbone. The catheter branches out into a couple of smaller tubes called lumens, which hang on the outside of your body. A sterile dressing covers the exit site at all times.

All chemotherapy drugs, transfusions and fluids are infused through these lumens or “ports”. Depending on your treatment plan, you may have several different types of fluids or meds being infused at the same time through different ports. Sometimes, if the drugs are compatible, you might have two different drugs going through the same lumen at the same time. A central line not only avoids needle sticks, it also prevents possible tissue damage caused by leakage of corrosive chemotherapy drugs (it’s rare, but it can happen).

How do I take care of my line?

Special care must be taken while bathing to avoid getting the exit site wet and your hospital may recommend that you don’t go swimming. A line must always have a sterile dressing covering it. Check with your medical team to learn how to change the dressing. Most hospitals will have a special teaching sheet to show you how to do this.

Your lines will also need to be flushed. How often will depend on the type of line and the hospital’s protocol.

Once you have your line in, you will very quickly learn how to take good care of it and what is best for you!

Subcutaneous (under the skin) or Implantable Lines

How do they work?

This type of line is usually referred to as a medi-port or port-a-cath (not to be confused with a porta-loo!)

Unlike a Hickman line, an implantable port is completely under the skin. This type of catheter is surgically implanted, usually in your chest but some people also have them in their arms. It is usually done with a general anaesthetic.

One end of the catheter is fed into a large vein leading directly into your heart. The other end is attached to a small chamber called a portal. The portal is made of either metal or plastic with a rubber top that seals it and is placed under your skin.

You will feel a small bump under your skin where the portal has been placed. When you need to use your port, it is accessed with a special needle (a Huber needle) that has a tube attached to it. Your meds or whatever will flow through the needle, into the catheter and then into your bloodstream. After a while, the skin over your port becomes very tough and insensitive, so you won’t necessarily feel it every time it is used. However at the start, to numb the area you can use an anaesthetic cream like EMLA.

How do I take care of my line?

Medi-ports and port-a-caths are easier to maintain than external lines. They also need to be flushed with a solution to prevent clotting, but usually only once a month or after each use.

You don’t have to worry about swimming or showering with these and you can still do your normal activities.

PICC Lines

A Peripherally Inserted Central Catheter (PICC) works along the same principles of a “drip”, but it can stay in for much longer...sometimes up to several months.

How do they work?

You may have a PICC line inserted for some of your treatment. Often they're used when treatment is short term or until a more durable central line can be surgically implanted. PICC lines are simpler and less invasive than other central catheters and can be inserted by a nurse.

The PICC is a thin flexible catheter, about 60cm long, which is inserted in your upper arm. It then feeds into the superior vena cava – the big vein just above the heart.

How do I take care of my line?

PICC lines are easier to maintain than some others. Your medical team will give you specific instructions how to care for your PICC line.

IV Cannula

You may have just a regular IV line (called a cannula) inserted for the time you are having chemo. These can only stay in for 24-72 hours, so will probably be used only a couple of times then taken out.

About IV pumps

How do they work?

Most of your drugs and fluids are infused over a period of time through an IV line that connects to an infusion pump. This pump keeps things flowing at a specific rate to ensure

effective dosing. Your meds, fluids and blood for transfusions are usually hung on an IV pole to which the pump or pumps are connected.

Depending on what you need, several different things may hang on an IV pole at the same time – chemo drugs, antibiotics, fluids, blood products, nutritional supplements etc. The tricky part is manoeuvring around with all this stuff attached to your body. You will soon get the hang of it and will know just how to move so all your lines don't get tangled up.

One more thing about those pumps...

Get used to them beeping! And learn how to use the silence button! The pumps “beep” when the infusion is completed. They also beep if there is air in the line (potentially serious) or if the battery is low. But beware – they often beep for no reason... very annoying especially when you're trying to sleep. You can hit the silence button while you're waiting for your nurse to adjust the pump. In the meantime, just grin and bear it.

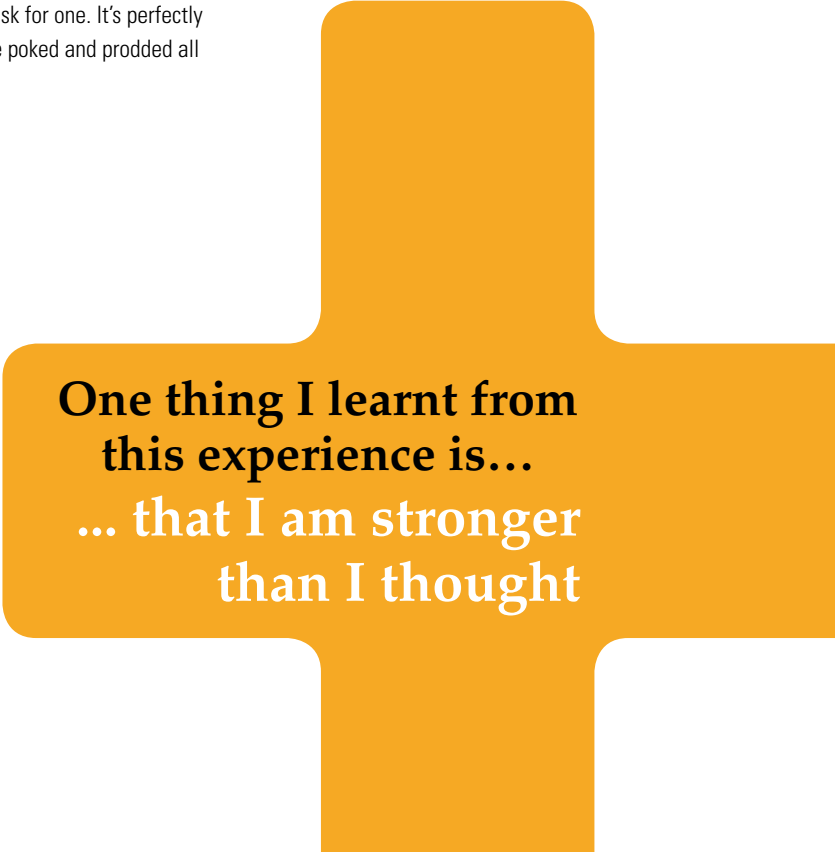
If you don't have a central line...

Depending on their treatment plans, some people may never have a central line. If that's you, you may need to have some IV procedures done with a venipuncture. This means a needle is inserted into a vein, usually in your arm or your hand. If you are having blood drawn, a tube is attached to the needle to collect your blood sample. If you are having drugs or fluids infused, IV tubing is attached through which

the substance flows. The same is true for a blood transfusion.

Getting stuck with needles for an IV is not usually that painful, but it's not exactly comfortable either. Some people are really good at it – others are not quite so good. Whenever possible, use a good dose of EMLA cream before the poke (it takes at least an hour to work). Also, if you are having routine IVs without a central line, try to keep switching veins (if you can remember). It will give them a little time to recover.

If you are being treated in an adult hospital, you might not get offered access to a line when you begin treatment (unless you are a haematology patient), but you can ask for one. It's perfectly okay to not want to be poked and prodded all the time!



**One thing I learnt from
this experience is...**
**... that I am stronger
than I thought**

GIVE IT TO ME STRAIGHT:

Does it hurt?



One of the biggest fears you have might be around pain.

Having cancer doesn't necessarily mean you are going to be in pain all the time or that all the treatments will be painful.

However, the truth is, pain is probably going to be a part of your cancer and treatment.

It is really important to tell your doctor and/or nurses if you are in pain – they cannot read your mind. No one will think you are being soft if you admit to being in pain. And unfortunately, there are no medals for being brave.

In most cases the pain can be managed – but you will have to be honest about it.



Remember

You have to tell people when you are in pain.



What causes cancer pain?

Most cancer pain is caused by the cancer itself or the treatments you receive. Major causes of pain include:

Pain from a tumour: If the cancer grows bigger or spreads, it can cause pain by pressing on the tissues around it. For example, a tumour can cause pain if it presses on bones, nerves, the spinal cord, or body organs. Sometimes, coughing, sneezing, or other movements may make it worse.

Pain from medical tests: Some methods used to diagnose cancer or to see how well treatment is working are painful. Examples may be a biopsy, spinal tap, or bone marrow test.

Pain from treatments: Some of the side effects of chemotherapy such as mouth sores, constipation or joint pain can be painful. You may also feel some pain after a surgical treatment.

There are lots of different ways to help relieve any pain you may have. The way it is managed and treated will depend on the cause of the pain and how bad it is

The aim of pain management is to keep you as pain-free as possible so that you can still do the things that you like to do as much as you can.

Everyone experiences pain differently and what really hurts for one person may not cause such a problem for someone else.

Try not to compare what is happening for you with other patients.

Dealing with procedures

When you know you are about to have a procedure, you might become really anxious. But being tense and nervous can make the whole thing a lot worse.

Being prepared for the tests and procedures can help with reducing the fear of pain. Ask the nurse or the doctor what's going to happen and make sure you understand what it all means.

Let your medical team know what things usually help you cope with painful or invasive procedures and make sure these are available before they start.

If you are freaking out or have had difficulties with procedures before, ask the doctor or nurse (or get your parents, partner or someone else you trust to ask for you) to help you develop a plan to make it less stressful.

You could also ask to speak with the psychologist at the hospital to help with some strategies. Most young people will see a psychologist during treatment. They will be able to help you manage your fears about needles and pain.

Things you could try:

- Using EMLA (an analgesic cream that numbs the spot where the needle is going in).
- Getting someone to distract you or just be there with you during the procedure.
- Listening to music while it is happening.
- Using some meditation or relaxation.
- If it becomes a big problem, hypnotherapy might help.

Finding ways to deal with these things can help you feel like you have some control over what is happening to your body.

Remember

The most important thing is to make this as easy as possible for you, so don't be afraid to ask for help.

Clinical Trials



Doctors, scientists and researchers are constantly working to discover and develop better ways to treat cancer. This is a long process that often happens over many years. The final stage of this process is called a clinical trial.

What is a clinical trial?

Clinical trials are research studies that test new and better ways of improving health in people. They find out whether new approaches to prevention, diagnosis and treatment are possible, safe and effective – by testing them out on people.

Clinical trials are the best way of developing better treatments and outcomes for people with cancer.

The most common types of clinical trial are ones that look at treatments. They test new treatments including:

- Drugs – such as chemotherapy and hormones
- Radiation therapy and surgical methods
- New ways to combine treatments

- New treatments like gene therapy, vaccines, antibodies and alternative therapies

These trials are designed by groups of medical specialists and include input from patients, nurses, statistical experts and support staff.

Is it safe?

Don't worry that if you sign up you will be a guinea pig in a mad scientist's lab test! That won't be the case.

The trials that most young people are involved in are called Phase 3 trials and they are about comparing the treatment being tested with what is already available.

They usually involve hundreds of patients across different hospitals and even different countries.

The treatment you will receive on a trial is just as good as, or even better than, the best treatment available.

“ The most useful piece of information I got was...
Don't let just one experience define you. Learn from it and take control of who you are ”

What are the benefits?

If you take part in a trial you will be monitored very closely and will probably receive extra attention. Any changes to your health will be picked up and acted on quickly. This includes things that are not related to the trial.

Because of this, people having their treatment within a trial often do better than similar patients treated outside a trial.

Knowing that you may help other young people who are diagnosed with cancer may also be a really positive reason to take part.

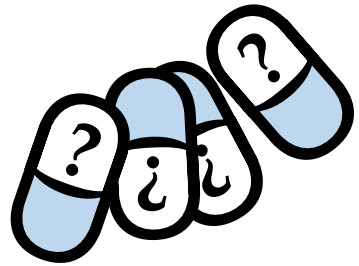
How does it work?

There will usually be two groups of patients involved in a clinical trial – a “control” group who will receive the best treatment that is already available and a “trial” group who will receive the new treatment. Deciding who gets which treatment is done randomly by a computer.

If you are in either group, you will have regular tests and you may be asked to answer questions about how you are feeling and what you are experiencing. This may mean you have to visit the hospital or your local doctor more often.

If at some stage during the trial the doctors discover that the trial is not good for you because it might not be working or the side effects are too bad, they will take you off the trial.

You can also usually withdraw from the trial at anytime if you want.



How do I decide if it's right for me?

- Talk it over with your parents.
- Make sure you ask as many questions as you want to and are sure that you understand what is involved.
- Ask for some written information so you don't have to remember everything.
- Don't feel rushed – it is a big decision.
- The doctors will respect your decision and if you decide not to do it, you will still receive the best treatment available.
- If you would like to take part in a clinical trial but have not been asked, you can talk to your doctor who may be involved in a suitable trial or can help you find one.

The Bald & *the* Beautiful



After reading about the different types of treatment for cancer you're probably thinking: "Hey, how's my body gonna react to all these drugs and X-Rays and stuff?"

Let's be honest. Your body WILL react to the treatments that you will get. We call these "side effects" and yep, they can suck big time. But your body has to go through some really tough stuff before it can get better.

Knowing what might happen – and being prepared for it – can take away some of the fear. The nature of the side effects and how long they last depends on your body, the type of cancer you have and the type of treatment given.

Side effects from cancer treatment can be either short-term or long-term.

Short-term side effects:

Short-term side effects can be very uncomfortable and difficult to deal with, but the upside is they'll generally go away once treatment finishes.

Hair loss

Some chemo drugs and local radiotherapy treatments stop you producing hair. This is because the drugs and therapy kills cells that reproduce quickly – which includes hair cells. Losing your hair can be one of the most upsetting side effects of treatment. It may be the thing that reminds you that you have cancer – and make your diagnosis really hit home.

But! While it can be really tough losing your hair, it is generally only a temporary thing!

It may come as a bit of a shock, but it's not just the hair on your head that may fall out. Your eyebrows, eyelashes, underarm hair and even your pubic hair may fall out, too. Like the hair on your head, it will grow back.

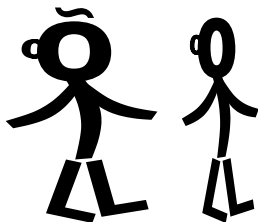
Your hair will usually start to grow back a few weeks after you finish treatment. But... your hair may be different to what it used to be. It may be thicker or thinner, curlier or straighter.

Some people don't experience any hair loss at all, or not much. If this happens to you, don't be worried that the treatment is not working! Whether your hair falls out or not is not an indication of how effective your treatment is.

When you know that your hair is going to fall out, the waiting can be tough. And even if you're prepared for it to happen, it can come as a shock.

Some ideas to help you cope with hair loss

- Discover your inner punk! Go for a Mohawk or dye your hair a crazy colour before you begin treatment.
- If you have the chance, ease into life-without-hair with a series of shorter haircuts.
- Have a shaving party with your friends and shave it all off before it falls out.
- Visualise yourself without hair (hello, Photoshop!). If you've got an idea of how you'll look, it won't come as such a big shock to see it for real.
- Find other things to put on your head like a scarf, cap, beanie, wig or a CanTeen bandanna!
- Learn to love and accept yourself bald – it's a new look for a little while. If you are comfortable with it, everyone else will be too.
- Above all, while it can be really tough losing your hair, remember it's only a temporary thing!



A bit about wigs

Whether or not you choose to wear a wig will depend on how comfortable you feel about your hair loss and the way it looks. Some young people get a wig and then decide that losing their hair is not as bad as they had thought.

If you think you'd like to use a wig, ask the social worker or the nurses where you can get one from. It might be a good idea to take some of your own hair (before it falls out) so that you can match the colour. You may be surprised how much a wig can look like your own hair.

You can take the wig to the hairdresser and get them to style it for you – it may be a chance for you to go for a completely different look (just remember if they trim it, it won't grow back!).

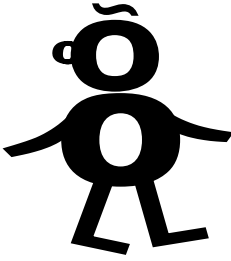
Weight loss

Some cancer treatments can make you feel less hungry or nauseous (like you want to vomit) and can cause you to lose weight. Losing a lot of weight can make it even harder to cope with the treatments and leave you without enough energy to do the things you like to do.

If you are getting thinner during treatment, eating foods high in calories and proteins might help you to put some kilos back on. Speak to the hospital dietician – they can advise you what food you should be eating.

The following tips might help:

- When you can, eat food that is high in kilojoules, like ice cream, cheese, yoghurt and milkshakes.



- Try and get lots of protein (meat, fish, eggs, nuts).
- Try drinking energy drinks like Ensure and Sustagen.
- Treat your eating like taking your medicine – just something you have to do to get better.
- Don't worry if there are only a few foods that you like – eat lots of those.
- Get out and about – a bit of exercise can help to keep up your appetite.
- If you can't face eating, don't stress. Keep up your fluids and try again later.

Weight gain

Other treatments may cause constant hunger and weight gain. These symptoms should go away when treatment stops, but unfortunately the side effects may remain.

One type of drug that affects weight is steroids. Steroids are natural substances produced by the body to regulate metabolism. But, when you have cancer you may need larger amounts than your body can produce to kill some cancer cells, reduce nausea, help with headaches and reduce swelling around some tumours.

The bad news is steroids can cause increased hunger and fluid retention which can lead to weight gain.

Many people gain a lot of weight on steroids. Your body fat might get redistributed in a different way too, which can be really distressing. One effect might be fullness in your cheeks, sometimes called "moon face". Unfortunately, though, dieting will not help to change this.

It's normal to feel self-conscious about gaining weight. But you may find changes to your body weight during cancer treatment particularly upsetting, especially on top of all the other stresses you are facing. Try to get through treatment and worry about the weight afterwards.

Tips for dealing with weight gain

- It might help to remember that steroids are an essential part of many treatment plans and that weight gain from treatment is usually temporary. Weight loss will usually start when treatment stops and you can start healthy eating and exercise programs.
- Don't avoid eating because you are afraid of putting on weight – it's getting better that is the most important thing.
- Focus on healthy eating to avoid real long-term weight gain. Drink plenty of water and eat fresh fruit and vegetables to "fill up".
- Exercise regularly if you can.
- Wear clothes that fit your size and that you feel comfortable in. Good excuse for a shopping spree!
- Talk about it! Let your family, friends or health care team know if you are feeling upset. Stress and depression can really make your healing processes worse.

Vomiting and nausea

Some chemo drugs may make you feel sick or nauseous. Usually, nausea will hit you a few hours after chemotherapy – and unfortunately it can last for quite a few hours.

The doctor can give you some anti-nausea medications, although it may take a while to find the one that works for you. It may also be hard to find foods that stay down and actually taste good.

Tips for dealing with feeling sick

- At the first sign of nausea, tell your nurse. Sometimes you can prevent nausea before it hits.
- Don't eat any favourite foods immediately after the treatment – they may never be favourites again!
- Keep a “barf bag” nearby at all times, especially in the car.
- Simple hunger often prolongs nausea. So have lollies or snacks between meals.
- Eat small, frequent meals rather than too much at any one time.
- Chop up food into bite-sized pieces to make eating less of an effort.
- Eat your main meal of the day at whatever time you feel best (great excuse for midnight snacks).
- Choose foods that don't have a strong smell (tip: foods that are cold or at room temperature will have less of a smell than warm foods).
- Choose fluids that'll give you some energy – like juice, milk or cordial.
- Rest after eating.

- Try eating with other people or while reading to take your mind off the food.
- Try getting fresh air whenever you can.
- Breathe! Deep breathing and focusing your attention may help to relax you and help to prevent vomiting.

Feeling tired and lacking energy



Feeling tired and not having your usual mojo is the most common side effect of chemotherapy. You might just feel like you can't be bothered doing anything at all and be unable to snap out of it. Even after treatment ends, tiredness may continue to drag you down. It is frustrating to have to do normal things at a slower-than-usual pace but try to be patient and allow yourself the time you need.

Things that can help:

- Eat well (when you can keep it down) and drink lots – it's important to help maintain your energy levels.
- Don't do more than you feel you can. Save your energy as much as possible.
- Try to do some light exercise.
- Take little nanna naps as often as possible.
- Let other people help you!

Mouth or swallowing problems

You may have a sore mouth or experience some problems swallowing food as a result of your treatment.

Things that can help

- Try sucking on a red ice block (has to be red – orange or pineapple ones are acidic and might hurt your mouth).

- Eat soft, smooth, blended, creamy foods that are kind on your mouth.
- Avoid foods that may sting your mouth such as acidic fruit or really hot or cold drinks.
- Avoid rough and crunchy foods such as nuts and chips.
- Try drinking liquids through a straw.
- Pay special attention to mouth hygiene to prevent infection and dental decay. Use a soft toothbrush and brush your teeth twice a day. Be careful brushing your teeth!! You may have a low platelet count and brushing your teeth may cause your gums to bleed. Try using a mouthwash instead.

Sometimes if you have really severe swallowing problems, the doctors may recommend putting in a nasogastric tube. This tube goes in your nose and down to your stomach. You can be given (liquid) food and medications down the tube, meaning you don't have to swallow. The downside is that they can be a little uncomfortable to have put in – but it usually only takes a few minutes.

Cognitive changes (a.k.a “Chemo Brain”)

Cognitive changes are problems with thinking, memory and behaviour.

Some cancers and some treatments can cause cognitive changes. These could include:

- Finding it difficult to concentrate for long.
- Feeling really vague and disconnected from the world.
- Disrupted sleep patterns.
- Memory loss, especially short-term memory loss.

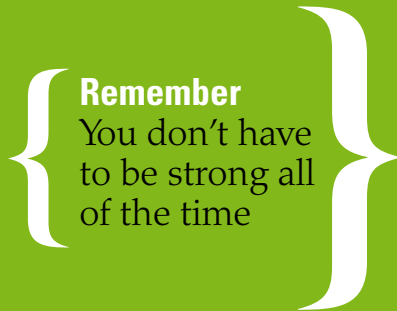
- Hallucinations.
- Disorientation (being confused about where you are).

Note: Cognitive changes improve with time.

Changes that occur because of certain medications will normally stop once the medicines no longer need to be taken.

Things that might help

- Keep a medication journal in which you write down the date, time and name of the medication you've taken.
- Take your medication at the same time everyday.
- Avoid possibly dangerous activities if you are alone like cooking, driving, using power tools or travelling to unfamiliar places.
- Ask for help when you need it.



Other short-term side effects

You may also experience any of the following things:

- Diarrhoea or constipation
- Irritated or sore skin on areas exposed to radiotherapy
- Acne
- Achy flu-like symptoms
- Increased blood pressure

Long-term side effects

Unfortunately, there can also be some long-term side effects from cancer treatment. These are side effects that are still there after you finish treatment. **But before you panic, most young people do not experience these long-term effects.** Your medical team will do everything they can to minimise the possibility of long-term side effects.

Every person receiving cancer treatment is unique – the treatment and effects will be different from person to person. Talk to your doctor about your own particular chances of developing these kinds of effects.

Graft-versus-host-disease (GVHD)

This can be a short or long term side effect, it just depends...

Sometimes when a patient receives bone marrow or stem cells from a donor (even if it's a brother or sister), the new cells (graft) react against their tissues (host). This reaction is called graft-versus-host-disease (GVHD). Essentially it's the donor's immune system attacking the patient's body.

There are medicines to prevent GVHD occurring and when it does occur it is usually mild. However, in some people it can become very severe and even life-threatening.

It mainly affects the skin, the gut (stomach and bowel) and the liver.

If GVHD occurs, it does not mean that the transplant has failed. It may even be helpful, as some of the cells involved in the reaction may also attack any cancer cells in the body that have survived the high-dose treatment.

TOP TIP: Go easy on yourself and know that help will always be there

Losing a limb

In some cancers of the bones and muscles, it may become necessary to remove a whole limb to stop the cancer from spreading. This is called amputation. It is only ever done if it is completely, utterly and totally unavoidable, usually because the cancer has spread from the bone and into the nearby blood vessels.

If the cancer has not spread in this way, a doctor may perform limb-salvage surgery, where the bone that has cancer is removed and the limb is saved from amputation by filling the gap with a bone graft or special metal rod. This is always done as a first choice.

Your doctor will talk things through with you so that you fully understand what is involved.

People who have amputations are usually fitted with a prosthesis, or artificial limb. These are very effective and many people with a prosthesis are able to return to normal activities – even sports.

Without stating the obvious, losing a limb can be one of the toughest consequences of your illness. On top of dealing with having cancer, you will also now have to adjust to a whole new self-image, or even a new lifestyle.

You will probably feel very scared and getting support is really important. There is a great online community for people who have lost a limb called www.lessthanfour.org. You can find other support options in "Where to get help".

Fertility

As a young person, your fertility (ability to have a baby) is probably something you have never really thought about.

However, some types of cancer treatment can affect fertility and it is a good idea to talk to your doctor about this possibility before you start treatment. There might be things you can do to preserve your fertility.

Although you might feel embarrassed or funny about bringing this up with your doctor, it is really important to just ask your doctor what your options are before you start treatment! You could ask something like, “Could the treatment I am going to have impact on my ability to have children – and is there anything we can do about it?”

If you’d like to know more, there is a book written especially about this called *Maybe Later Baby*. Check out “Recommended Reading”.

Hearing loss

Some cancer treatments can cause damage to the inner ear, resulting in temporary or permanent hearing loss, dizziness or ringing in the ears (tinnitus).

If you have hearing loss, your doctor might recommend that you be fitted for a hearing aid. Research is ongoing to find new techniques to manage this side effect and there are a number of things you can do to help manage hearing problems:

- Avoid loud noises to prevent further damage.
- Drink plenty of water to avoid dehydration, which can worsen symptoms.
- Avoid stress, anxiety and fatigue.
- Use a quiet radio, television or any low level sounds when you are trying to rest. The background sound may help you ignore the tinnitus and make it easier to sleep.

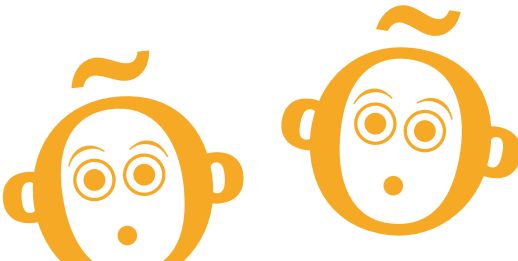
Cardiac (heart) and lung (pulmonary) problems

Radiotherapy to your chest or upper back can sometimes damage the heart and lungs.

Chemotherapy drugs like doxorubicin can temporarily change the rhythm of the heartbeat. In most people this will go back to normal after treatment, but with high doses or repeated treatments of doxorubicin, there is a small risk of long term heart damage.

Other drugs, such as bleomycin, can cause inflammation of the lungs, which can also cause breathlessness. If you have a lot of bleomycin in your treatment regime, it can cause permanent breathlessness from scarring (fibrosis) in the lung.

If your doctors think you might have increased chances of developing these long-term effects, they will tell you and you’ll have regular checks with echocardiograms (heart ultrasound) and lung function tests to minimise the risk as much as possible.



who is that person?

You will be treated by a whole team of people. Sometimes trying to remember who does what can be a bit confusing. This chart will help. The blank column is for you to write in the names of the people who are looking after you.

There may be more than one person who is doing the same job or you may not have all of these people on your team.

Who are they?	What do they do?	Their name
Medical Team		
Medical Oncologist	A doctor specialising in diagnosing and treating cancer patients.	
Radiation Oncologist	A doctor specialising in radiation to treat cancer. This doctor will decide if radiation is an appropriate treatment, will choose the best form of radiation treatment and then administer it.	
Surgical Oncologist	A surgeon who specialises in removing cancers via an operation.	
Radiologist	A specialist doctor who interprets X-Rays, MRI scans and CAT scans to get pictures of the body.	
Oncology Nurse Specialist	A registered nurse with additional education and training in cancer.	
Registered Nurse	A nurse who provides regular care in the hospital or outpatient clinic.	
Cancer Care Coordinator	A nurse who is the main point of contact and helps patients and families communicate and deal with the different members of their treatment team.	

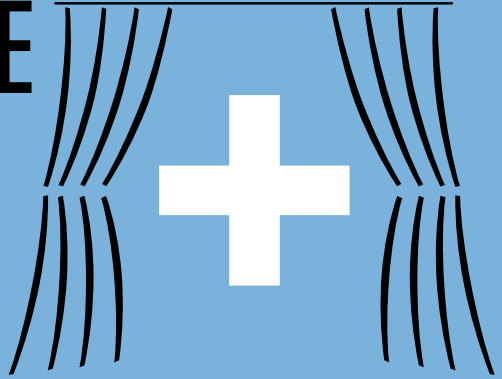
Med Stuff/Who is that person?

Who are they?	What do they do?	Their name
Multidisciplinary team		
Social Worker	A trained professional who helps patients and their families adjust to life with cancer and treatments. They can help with things like support services, financial assistance and other practical issues.	
Clinical Psychologist	A professionally-trained therapist who helps with emotional and intellectual well-being during cancer diagnosis and treatment.	
Dietician	A professional who provides information to patients and their families about nutritional needs related to their cancer and treatment.	
Pharmacist	A professional who is knowledgeable about drugs and medications that may form part of your cancer treatment.	
Physiotherapist	A professional who helps with recovering physical movement, like walking, bending and strengthening and may help with your recovery after surgery.	
*		

* You might also get other people helping, like someone to assist you with any school work you have missed.

BEHIND THE CURTAINS

AN INSIDER'S GUIDE TO HOSPITALS



Once cancer enters your life it's pretty likely you'll spend some time in hospital, either as a day patient or for longer stays.

So...what's it like?

Some people can't stand hospitals, but others don't really mind at all. It might depend on how long you have to stay.

Checking in

When you first are admitted, be prepared for heaps of questions. Some, like your address and date of birth, you will be able to answer but others your mum or dad may have to answer for you. They will want to know about past illnesses, accidents, if you are allergic to anything. This is important to know for your treatment but also just gives them an idea of what they can do to make things as comfortable as possible for you.

They won't quiz you every time you come in. All this info is kept in your medical notes

so that when you go in again they'll just ask about your health right now.

You may be sharing a room with other people who are undergoing cancer treatment, or you may be in your own room. This depends on the hospital and also your treatment. If you have a chance of developing an infection, you may be in a room by yourself.

Will I be in bed all day?

Of course you are there to be treated for your cancer, but you may be surprised to discover that you won't have to stay tucked up in your bed all day.

If you are feeling OK, you can get up and wander around. Most children's hospitals (OK, you might not be a child but that's what they get called) have places where you can go and do stuff like watch TV, play computer, do some art. If there are other young people your age you can hang out together.

You can also be dressed – and leave the PJ's for night time. This might help make things feel a bit more normal.

Other patients

When you first get admitted into hospital, you might be a bit overwhelmed by the other patients in your room.

Some of them may be really sick or in different stages of their treatment. You may be scared that this is what will happen to you.

Try not to compare yourself to anyone else as everyone's cancer and treatment is different.

What about visitors?

Each hospital has different rules about who can visit, for how long and when. It may also depend on what treatment you are having. Your parents should be able to be with you as much as you want and they can usually stay overnight at the hospital.

Unfortunately, most children's hospitals are designed for little people and you may find that lots of the patients in hospital are going to be whole lot younger than you. This can make hospital stays even more challenging. Your idea of early or late and what is noisy might be really different to the other people in the ward.

You will also have to get use to losing quite a lot of privacy. If you are on a shared ward, it might help to pull the curtains around your bed.

If you are more likely to get an infection because of your treatment and are in a room by yourself, your visitors might also have to wear gloves and hospital gowns to enter your room so they won't pass any germs on to you.

Tips for loooong hospital stays

Unfortunately, it's not exactly *Grey's Anatomy*. Long stays in hospital can be really boring.

Here are some tips from other young people that might make hospital stays more bearable:

- Decorate! Bring your posters, pillows, photos and other favourite stuff from home and make the hospital room feel more like your own space.
- Have a "bedwarming" party. Your friends may not realise you want them to visit you in hospital. Invite them to come and hang out, play cards, watch TV, catch up on the gossip. Maybe they can even sneak you in a bit of real food...
- Make a visitor book or poster for visitors to sign and leave messages.
- Take pictures of people who come to visit. This can be fun and nice to look at once you're out of hospital.
- Bring airsprays, incense or perfumes to hide the smell of your hospital room.
- If you don't feel like talking to anyone, unplug your phone or make a "Do Not Disturb" sign to let people know you're not up for visitors.
- Get to know the night nurses well. They'll save you from insanity when you can't sleep!
- Take control – you can still be involved in decisions, so don't be afraid to speak up. Decide when you want to be awake or asleep. Tell people if you don't like the hospital food.

- Beg, borrow or steal (no, actually don't steal) as much media as you can – a laptop, books, magazines, DVDs. Load some new music onto your iPod and get your friends to add playlists for you.
- Start a journal, a blog, poems, a novel...
- Learn to knit. Impress the grannies in the bed next door.
- Find your release – art and craft, scrapbooking, puzzles, games, crosswords.
- Make concrete plans about things you will do when you get out of hospital. It helps to have something to look forward to.
- If you can't muster the energy to read but would love a good story to distract you, try an audio book. Entertainment with your eyes closed – bonus!
- Make some new friends. Find out if there are other young people in hospital and see if you can meet up.
- There are also heaps of secure networking sites and online bulletin boards for young people who are going through similar experiences to you. You can chat online and exchange battle stories.
- Get outside the hospital or ward if you are well enough. Some fresh air and sunshine can make a nice change.
- Ask your friends or school teachers to bring things from school for you to do.



Cultural differences

Whether you have to travel far for treatment or just around the corner, hospitals and clinics are a different world and the people and environment might be really different from what you are used to.

There may not be many people from your cultural background working in the hospital. You might find it difficult to talk to the doctors about symptoms and personal issues and feel a bit isolated or uneasy.

If you want to, you can ask to speak to an Aboriginal Liaison Officer or Transcultural Services Coordinator in your hospital who can offer relevant support. There may also be translation services available.

If you don't feel comfortable with private consultations, you can take someone with you to your appointments. You can also request to be treated by a male or female doctor if you prefer.

Going home from hospital

While you are in hospital, there are always people fussing over you, telling you what to do, when to wake up, what to eat and what treatments you will be having. You may be really looking forward to going home and getting back to normal.

So why can it feel pretty scary when the day actually arrives?

If you have been in hospital for a long time, you may have become used to all of the attention you received from nurses and medical staff, and also from your family and friends who came to visit. You have probably also become used to the hospital routine and always having people around you who know and understand your situation.

So when you leave the hospital, you might find that it is not that easy to settle back in at home. You might miss your doctors and nurses and the security of hospital life and worry that no one will be there if something goes wrong.

It's normal to feel a bit anxious when you are dealing with major changes. But know that you will be OK and that support will still be there for you even after you leave the hospital.

There are some things you can do to help you feel more comfortable with the move back home:

- Have the phone number of the hospital and your doctor somewhere in the house where everyone can see it – and remember that you can call them anytime you need to.
- Arrange for the nurse or social worker from the hospital to check up on you for the first couple of weeks.
- Have a plan of action so that everyone in the house knows what to do if you get sick.

Without all those treatments, procedures and appointments to focus on, all of the emotional stuff that you are dealing with might seem to suddenly hit you too. It can be really hard to get used to being treated the same as everyone else again. See "What's a coping strategy?" for some tips on how to deal with difficult feelings.

“

One thing I have learnt is...

**... Everyone will react differently –
some better than others**

Staying HEALTHY



Seems like a bit of a contradiction – staying healthy while being treated for cancer! Are you serious?!

Well, actually, yes.

Even though cancer can make you feel quite sick, staying as healthy as you can while being treated will help your body recover from the treatments and give you the best chance of coping with it all.

Healthy Living 101

Eating well

There are going to be times during your treatment when food is not exactly going to be your best friend. But a good diet is really important during treatment. Your body needs extra fuel to fight the cancer.

Losing a lot of weight can make it harder to cope with the treatments and also means you may not have enough energy to do the things you do like. Speak to the hospital dietician – they can advise you on what foods you should be eating.

For some tips on how to keep your food in your stomach instead of in a bucket, see the ideas for dealing with vomiting and nausea on page 39.

Exercise

While you are throwing up or completely wiped out from treatment – just getting up out of bed may be a huge achievement. Exercise is probably the last thing you feel like doing.

But even a small amount of exercise is good for your body and also good for the mind.

No-one is talking running a marathon or playing five sets of tennis, but a small amount of gentle exercise can be really good for you.

Exercise can help to:

- Increase your energy.
- Improve your sleep.
- Manage your weight better especially if you are on steroids.
- Keep your bones strong.
- Deal with the emotional ups and downs of cancer and treatment.

Infections

If you are having chemo and/or radiotherapy then you have a higher chance than other people of getting an infection. This means your “immunity” is lowered. A simple infection can quickly become quite serious when your immunity is down.

To lower your chances of getting an infection you should:

- Stay away from people who are sick – even if it’s just with a cold or flu.
- Ask friends and relatives to tell you if they are sick or have been in contact with someone who is.
- Wash your hands often and well.
- Be careful with what you eat. Make sure your food has been washed and cooked properly.
- Use sterile procedures when you clean your central lines.
- Call your doctor straight away if you develop a temperature or other symptoms like a sore throat, rash, ear ache or upset stomach.

If you think you might have an infection, call your doctor immediately.

Sleep and relaxation

Even though you may feel very tired a lot of the time, many people with cancer find it hard to actually drift off. You may be kept tossing and turning due to stress, pain, fevers, nausea or the treatment drugs you are taking.

Not getting enough sleep can affect your mood and concentration and can make the stresses of cancer even harder to deal with.

A good night’s sleep of between 7 and 8 hours will make a lot of difference. Here are some techniques you can try to help you relax and fall asleep when counting sheep just doesn’t work:

- Try to wake up and go to bed at the same time each day.
- Try not to let your room get too hot or too cold.
- Avoid cola drinks or coffee a few hours before bedtime.
- Wind down at the end of the day by listening to music, watching TV or reading a book.
- Know when to give up – if you are still awake after 15 or 20 minutes, try reading or doing a boring task until you feel sleepy. Tossing and turning and worrying about all the sleep you are missing can make it worse.



TOP TIP: Don't give into peer pressure thinking it will make things better

Drugs and alcohol

You or some of your friends might have already started to experiment with drinking alcohol, smoking or taking drugs. We'll skip the lecture, we know you know – drugs and alcohol are not good for you at the best of times. And they really don't mix well with cancer.

Drugs and alcohol can interfere with your treatments, increase the impact of any side-effects and increase your chance of getting an infection. They also make it harder to think clearly and make good decisions.

It is important that you are honest with your doctor about any drugs and alcohol you are using or have used in the past. Anything you tell them will be kept confidential. Doctors are not going to judge, they just need to know the truth.

Other stuff

Some people you know might be starting romantic relationships and having sex. If you want to know more about how cancer and treatment might impact on your ability to have sex, talk to your medical team about it or find more info at www.nowwhat.org.au .





The graphic features the words "when to worry" in a bold, black, sans-serif font. The word "when" is positioned at the top left, "to" is at the top right, and "worry" is at the bottom. A stylized alarm clock icon is integrated into the letter "O" of "worry". Small zigzag lines are placed around the words "when" and "to".

Don't ever feel afraid or embarrassed to call your doctor or their team. They are there to answer your questions, even when you are not in hospital.

It is sometimes hard to know what a normal reaction to treatment is and what is something that you need to worry about. Ask your doctor to give you a list of things that you should particularly look out for and when it is really important to call the doctor or hospital.

You might have to look out for these signs or symptoms and call the hospital if you have:

- A temperature 38°C or above.
- Any sort of bleeding (including from the gums, nose or when you go to the toilet).
- Noticed that you are bruising more easily than usual or have red/ purple spots on your skin.
- Headaches.
- Any kind of coughing.
- A change in your appetite.
- Vomiting a lot.
- Much less energy or are more vague than normal.
- Any change in your toilet habits – such as more often, less often, painful or stained with blood.
- A sore throat, rash or ear ache.

Fevers

Having a “fever”, a “temperature” or being “febrile” can occur at anytime during your cancer treatment. Having a temperature may be a sign that you have an infection, even if you are feeling fine. While you are on cancer treatment, some infections are life threatening and an urgent response to a temperature will prevent further complications. While you are on treatment, it will be difficult to fight an infection on your own, and you will probably need to start antibiotics right away.

Ask your medical team for information about exactly what to do if you become unwell.

They can tell you at which temperatures you need to worry and get to hospital. If you think you have a high temperature and are unsure, call your medical team or the hospital straight away.

Things to remember:

- Before you take Panadol for a temperature, make sure you have contacted your medical team or the hospital first.
- If you get a temperature at night, do not wait until the morning to go to hospital, you must go right away.
- Call your doctor, nurse or the ward if you are not sure what to do.
- Ring the hospital ahead, to let them know you are on your way in. This may help speed things along once you get there.
- You may need to spend a few days in hospital, so pack a bag to take with you just in case!

Chicken pox or measles contact

It’s important to tell your friends and family that they must not visit you if they come out in the measles or chicken pox rash. Sometimes, they might come out in chicken pox a couple of days after they have been with you. It’s important that they tell you straight away if they do.

If you hear that anyone that you know or that you’ve been hanging out with gets the measles or chicken pox, tell your medical team so they can take steps to stop you from getting sicker.

Disprin/Aspirin/ Nurofen/Ibuprofen

There may be times when you might need to take something for pain, but you should ask your doctor before you take anything.

Remember
Think positive, stay active



Dealing with your cancer can bring up all sorts of different feelings. Some of the things you feel might come as a surprise to you. And at times you may find it difficult to pinpoint what it is you are actually feeling or understand why.

The main thing to remember is; there is no right or wrong way to feel.

Many young people have described having cancer as like being on an “emotional rollercoaster”. You feel like you are racing along with no control and experience massive ups and downs on the way.

You might not be naturally comfortable with sharing your feelings and sometimes you hope that if you just ignore them they will go away. (Guess what?...They don't).

Feelings are not good or bad, they are just feelings. Even if you keep them hidden or try to ignore them, they will still just be there.

The problem is that when things get bottled up they need to get out somehow and this can lead to behaviour that is not safe, angry outbursts or a bit of a meltdown. As hard as it may be, finding some ways to express what you are feeling is really important in helping you to deal with the stress of living with cancer.

Sometimes it helps just to put a name to what you are feeling:

Shock/disbelief

"Cancer? OMG!" Even if you suspected something was up, you probably didn't think it would be cancer. When you were first diagnosed, it might have felt like you were watching it all happen from far away. You couldn't focus on what the doctor was saying and had to keep asking the same questions over and over. Maybe you cried, maybe you just felt numb and emotionally drained. These are all normal reactions to shock.

Scared

Doesn't matter how tough, mature or brave you are – finding out you have cancer can scare the crap out of you. Some fear may be based on facts about what will happen or about the changes to your life. But other fear is based on things imagined. Most people feel less scared when they know the honest truth about what to expect. Learning about your cancer and its treatment can help. Admitting that you are afraid, and that it's ok to be afraid, can also be a big relief.

Uncertainty

While there are advancements in medical knowledge being made all of the time – and it's a fact that most young people do survive cancer – it is impossible for a doctor to give a 100% guarantee that your treatment will be successful or that cancer will never return. This uncertainty can be one of the things that sucks the most about having cancer. You don't know what's going to happen or how to plan for the future.

But it is possible to live with uncertainty and not feel overwhelmed by the things that you cannot control.

Angry

Feeling angry is normal – and totally understandable! You might feel like it's just not fair, want to know WHY it's happened to you, and then get mad at yourself for feeling that way. Anger can range from mild irritation to full-blown rage. Sometimes anger can hide other feelings like fear or sadness.



You might get snappy at your family, friends, doctors and nurses and everybody else sometimes. That's normal too, so don't feel guilty.

It is OK to feel angry, but there are good and bad ways to express it. See "If it all seems too much" for some tips on releasing the rage.

Sad

There are lots of reasons to feel sad when you have cancer. Sadness may come and go. But if you find that it doesn't seem to go away, that it is starting to get in the way of other things, or that you are starting to lose hope that things will get better, then you might be depressed. Depression is a serious condition, but it can be treated. For more on depression, see "If it all seems too much".

Frustrated

You may feel like you have lost your independence and can't do anything for yourself anymore. You feel dependent on other people and always told what to do. This can make you impatient and short-tempered.

Guilty

Guilt can strike for all sorts of reasons. You might blame yourself for getting cancer. You might feel bad that you are causing your parents to worry so much, or that your cancer has messed things up at home. You might feel guilty for surviving while others did not.

It's easy to get caught up with guilt. Try to remember that it's not your fault that you have cancer and life has been turned upside down. Often acknowledging guilt is the first step in letting it go.

Embarrassed

You might be embarrassed about some of the feelings your cancer has brought up in you. You may look different or act differently because of the cancer, and people may ask annoying questions that you don't know how to answer. This isn't always easy to handle. If you feel up to it, try thinking of some creative comebacks to deal with starers – maybe you can tell people that your treatment scars came from being bitten by a shark??



Jealous

It's not uncommon to feel jealous of your brothers, sisters or friends because they don't have cancer and can still go out and do stuff and have a normal life.

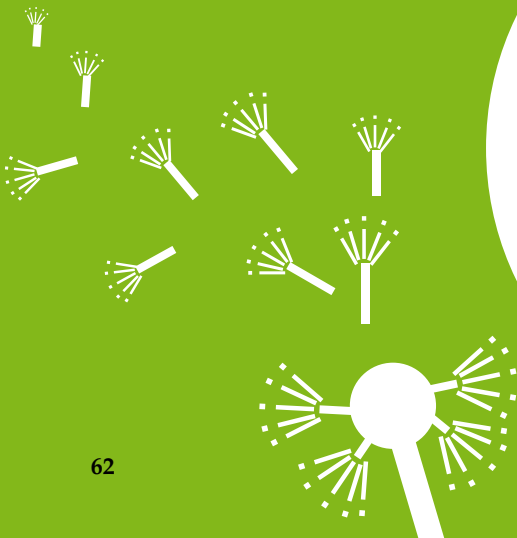
Lonely

Having cancer can make you feel very alone, even if you are surrounded by your family and friends. You might feel that no one really understands what you are going through. Your friends and family might not know how to deal with your cancer and start to treat you differently, or just stay away. You might be spending long periods in hospital and miss going to school, uni, work or your usual social activities. Having to face cancer can cause you to grow up faster than your friends and you might not relate to them so well anymore.

Having cancer can feel very isolating, but it might help to remember that there are other people out there going through it too. For where to go to connect with people facing a similar experience, see "Where to get help".

Withdrawal

There may be times when you feel really down and just want to be left on your own. This is OK, but if you find you are shutting yourself off most of the time and never want to talk to anyone, this may also be a sign that you are depressed. (For tips on dealing with depression, see If it all seems too much).



Staying positive

You might feel (or people might be telling you) that you should “think positively” when you have cancer. It's true that it helps to be optimistic and hopeful, but you are not expected to feel happy and cheerful all of the time. Having cancer may be one of the biggest and scariest things that will ever happen to you and it is totally normal

to be worried and upset by it. Feeling sad won't delay your recovery, and crying or talking about your fears can actually release stress and make you feel better. Despite what people may say, feeling negative about your cancer experience will not affect how well the treatments work, or make the cancer worse.

“

The most useful piece of information I got was...

... it wasn't my fault that cancer happened. It's reassuring to know that you are not to blame for it

N W H A T ' S V S
B A A W G H O R F
S C F D S F L H J
G D O E Q S D S D
D F F P V Y U I O
I O P P I B F D B
N R D G P N D N R
S F D F P O G I Y
S T R A T E G Y ?

“Coping strategy” is a fancy term for those thoughts and actions that help you deal with the tough stuff that living with cancer can throw at you. Coping is not just putting up with a problem, but bringing it under control and finding a way to feel better.

Do I need one?

Yep – in fact you’ll probably need a few. You are likely to be facing a lot of stress and anxiety and it is important to manage these feelings so that they don’t further impact on your health.

It’s really important to find the best way to get by – and only you know what that is.

Everyone deals with stuff in their own way and what works for others (even those in your family) may not work for you.

Things you can try:

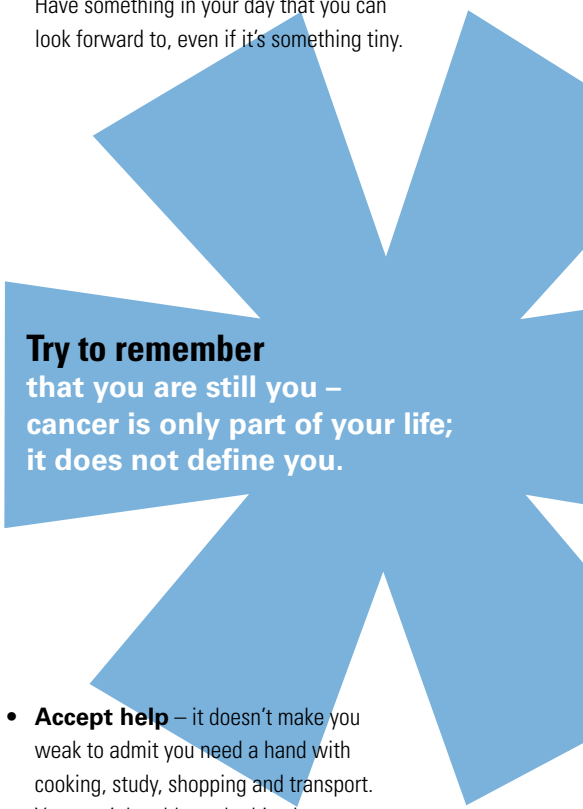
- **Learn about your illness** – some people feel more in control when they can understand what is happening and what to realistically expect. Let your doctor know how much or little you want to know.
- **Ask questions** – don't be afraid to ask anyone anything concerning your cancer. Ask doctors, nurses, parents. Write the answers down. Ask again if you still don't get it. It's better than presuming the worst.
- **Get involved** – become an active member of your treatment team. Find out about procedures, results, choices. Regain control and independence. Decide when you want to be woken up, decide what you want to eat, watch or listen to.
- **Look after yourself** – your doctors and parents are more likely to give you back some of your independence if you can prove you can take care of your own medications, dressings and make healthy food choices.
- **Talk** – expressing how you are feeling is better than bottling it up. Find someone you can trust and just vent. Go on... you deserve a good rant. Sometimes this person will not be a close friend or family, but someone who may randomly come into your world at this time.
- **Hang out with the right people** – avoid people who make you feel stressed, embarrassed or uncomfortable.
- **Write a journal or blog** – you could share it with the world or keep it to yourself.
- **Eat chocolate** – yep, we said it's OK.
- **Laugh** – try to find some ways to have fun and be silly every so often! Read a funny book or watch a funny movie.
- **Set goals** – a short-term goal might be to finish the book you are reading, or to eat more protein. A long-term goal might be to get back to school or work 4 days a week.
- **Stay positive** – remain hopeful that this is a temporary thing and that you won't feel this way forever.
- **Cry** – let yourself and others give in to the waterworks sometimes.
- **Get organised** – things like a weekly planner and to-do list can help things seem a bit more manageable. Be realistic about what you can fit into a day or week and don't take on too much.
- **Release your inner Picasso** – find ways to release your emotions through creative activities like arts and crafts, music, writing or photography. It doesn't have to be good; smash some drums, mess around on a piano, scribble with crayons.



Try to remember
take some time
out for yourself
– do things that
you want to do



- **Keep doing normal things** – hang out with your friends, play sport, listen to your favourite music and try to do as many of the things you used to do as possible. It helps to stay in the loop about the latest movies, songs, news and gossip. The internet is awesome for this.
- **Have a makeover** – it might make you feel better about yourself and your new appearance to change your hairstyle, buy some new clothes or put a bit of makeup on.
- **Exercise** – a walk, swim, yoga or bike ride a few times a week can reduce stress and help you to feel better, (but talk to your doc first!).
- **Eat chocolate** – did we mention that?
- **Live life** – try to do as many of the things that you did before the diagnosis that you feel you can.
- **Try something new** – ever wanted to learn guitar? You may have heaps of extra free time and find that learning something new might help to distract you from the worries of cancer and give you a sense of achievement.
- **Get plenty of sleep** – when you're really tired, emotions and stress can be even harder to deal with. See "Staying healthy" for tips on sleep.
- **Learn how to meditate** – you will be amazed at how good this feels.
- **Tap into your spirituality** – not just traditional religion but anything that may give you comfort.
- **Maintain a routine** – try to get back to a daily routine and normal home life as soon as practical after your treatments. Have something in your day that you can look forward to, even if it's something tiny.



Try to remember
that you are still you –
cancer is only part of your life;
it does not define you.

- **Accept help** – it doesn't make you weak to admit you need a hand with cooking, study, shopping and transport. You won't be able to do this alone.
- **Join a support group** – get in touch with people who understand what you're going through and can share tips and info. You can find support groups in "Where to get help".

The way you feel about losses like these is called grief. Grief is a normal, healthy response to loss and it can help you adjust to the loss.

It is important to recognise when you are experiencing grief so that you can cope with it and get some support.

You may be experiencing grief if you notice some of these behavioural changes:

- Having trouble sleeping or wanting to sleep all of the time.
- Having sad dreams or nightmares.
- Eating heaps or not wanting to eat much.
- Crying lots and feeling extremely sad.
- Avoiding things, places or activities that remind you of what you have lost.
- Wanting to be alone or not wanting to talk to anyone.

Grief is a personal thing.

There is no right, wrong or “normal” way to do it and how long it lasts will be different for everyone. Don’t compare yourself to others and don’t be embarrassed by how you feel.

It’s hard to imagine now, but it won’t always feel this hard. Grief is not a single event, but can come and go in waves and you will have good days and bad days. Try to be patient with yourself.

Putting a lid on it and hoping it will go away isn’t always the best way to deal with grief. It is important to get support to deal with these things and to help you to make adjustments in your life.

Usually, the best way to cope with grief is to express it. So let yourself feel sad and try to release your feelings.

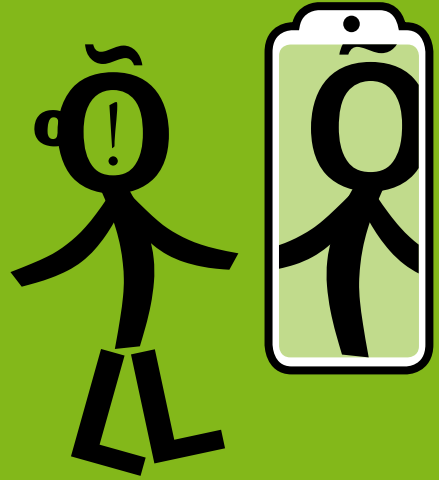
Remember: Your grief is your own. You might have to ignore people who tell you just to “move on” or “get over it”. Only you know how you feel.

“

**One thing I have learnt is...
... no matter how endless or terrible the
ordeal, it always passes.**

OMG, IS THAT REALLY ME?

Dealing with changes to your body



At some stage during your cancer treatment you might look in the mirror and think “who is that person?”

Treatments for cancer can really change your appearance, whether it’s weight loss or gain, loss of hair or scarring. Your body may look and feel like a foreign object that’s not even connected to you. You may be uncomfortable about your appearance and about feeling different.

The good news is that with time, your appearance and feelings about your body will change. It may take time to get used to, but it will become easier.

You might feel:

- Loss of confidence and self esteem – you might be really self-conscious of your physical changes and avoid doing things you used to do like going to the beach, playing sport and wearing the clothes you used to.
- Shy – you don’t feel like hanging out with friends or going out in public.
- Frustrated – that your body doesn’t work like it used to.
- Angry – it is not fair that you had to go through this and that you had no control over the changes that have happened to your body.
- Nervous – that you will be laughed at or stared at.
- Embarrassed or ashamed – about the way you look now.
- Grief – over the loss of your ‘old’ body.
- Scared – that your friends, partner and colleagues will treat you differently.
- Worried – about being less attractive and not being able to find a boyfriend or girlfriend in the future.

Even changes that are not visible on the outside can have an impact on how you feel about yourself. It doesn't make you vain or selfish to be worried about your body and how people see you.

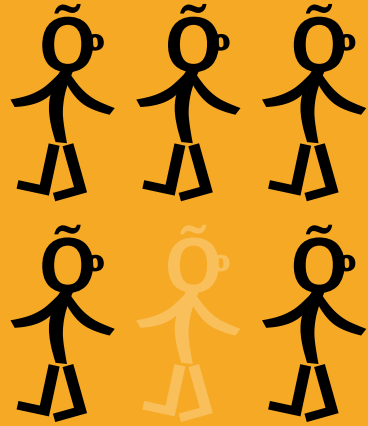
Things that may help you cope with changes to your appearance:

- Have a makeover. Experiment with a new look. A new wig or hat, some makeup or some clothes to fit your new size might make you look good again....even if you don't feel it.
- Try to focus on other things that will give you confidence besides the way you look. You may want to take pride in your positive outlook...think of the amount of love and support you are receiving from those around you.
- Talk about it. Your family and friends may not realise how much the change to your appearance is worrying you. The truth is, people will understand.
- Try to treat your body with respect. It's been through hell and back already. Eat healthy foods, get enough sleep and only exercise as much as your body can handle.
- Hang out with the right people – people that make you feel good and accept you for the way you are.
- Keep in mind that people stare and ask annoying questions because they don't understand cancer or what you are going through. Depending on how you feel at the time, you could take it as an opportunity to educate them...or maybe you can come up with some creative comebacks?
- We know it's a cliché, but try to remember that you are the same person and that your personality, interests and talents are still there. You are not your cancer.

Top Tips

Acknowledge that you feel sad.
You are not overreacting

Dealing with losing someone



While you are being treated for cancer, you might get to know other people who have cancer. You might find they understand what you are going through better than your other friends and become an important source of support for you.

But everyone's cancer journey is different and the sad truth is that not everyone will survive cancer.

Coping with the loss of a friend while you are unwell and going through so much of your own stuff is incredibly hard and downright unfair.

Things you might feel:

- Sad – this can feel like a deep heaviness inside you and you might think that you will never laugh or smile again.
- Lonely – you may feel that you are the only person feeling like this.
- Afraid – you might be reminded that cancer can be life-threatening and cause you to think more about your own life and illness.
- Guilty – for surviving when your friend didn't.
- Angry – there are lots of things to be angry about: at your friend for leaving you behind; at cancer and the whole situation.

You might feel like you're going crazy, but these thoughts and feelings are all normal expressions of grief. **Whatever reactions you experience are normal for you.** Ask yourself how you feel and try to be as honest as you can. Putting a name to your feelings can be the first step in coping with them.

Coping with guilt and grief

There are no rules for grief and it is not a test or a competition. Don't let other people tell you how you should feel.

Feeling guilty that you survived cancer when others didn't make it is a normal reaction. But it is not your fault that they died so don't blame yourself.

You don't need to feel like you survived for a reason. Every cancer is different and every person's reaction to the treatment is different.

Dealing with guilt and grief starts with recognising it and talking about it openly. Unfortunately denying it or avoiding it usually doesn't make it go away.



Try to remember

You *will* get through this! As **unbelievable** as it might seem now, things *will* get **easier**.



Helpful hints

- Let yourself grieve – it should help.
- Don't expect too much of yourself. Don't be frustrated with yourself if it takes a long time to work through this.
- It's OK to laugh and enjoy things. There are a lot of good things in life, even in the tough times.
- Ask for help if you need it.
- Talk about or think about the person who died. Try writing letters, poems, stories or making a scrapbook to remember them.
- Say goodbye. Attend a funeral or celebration of life.
- Talk to your parents or favourite health professionals about how you are feeling.

**if
it all
seems
too
much**



When you are living with cancer, it is normal for you to experience a heap of mixed emotions and for everyday things to seem hard. However sometimes things can start to seem like they are out of control and it can feel like it is all too much.

It's really important to recognise some of these warning signs that you are not coping and to get some help.

Depression

It is normal for you to sometimes feel sad and down while you are dealing with the stress of cancer. But if a sad feeling goes on for a long time and starts to hurt so deeply that it's hard for you to enjoy the good things in your life, it is called depression.

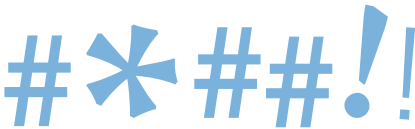
Some common signs and symptoms of depression are:

- Feeling sad, moody or miserable most of the time.
- Feeling like there's nothing to look forward to.
- Being unable to feel good or enjoy things you do normally.
- Becoming really quiet and withdrawing from your family and friends.
- Being unable to think about much other than cancer or death.
- Sleeping too much or not enough.
- Crying a lot for no reason.
- Eating too much or not enough.
- Problems with concentration and memory.
- Having headaches or feeling sick in the stomach.

Beating the blues

If you have a few of these symptoms and find they are not going away after a couple of weeks, it is important to talk about it. Try not to panic – depression is very common and there is help out there for you.

You could talk to your parents, doctor or social worker about it. There are also phone numbers you can call to get help (see the phone numbers and websites in “Where to get help”).



Anger and stress

Having cancer can, understandably, really p*ss you off. You might feel like it's not fair, that you've done nothing to deserve it, or just feel angry that things feel so out of your control. You might feel frustrated because you can't do all the things you used to, or just sick and tired of being stuck in hospital.

Being angry is totally normal, but remember that there are helpful and unhelpful ways of dealing with it.

Releasing the rage:

Anger sometimes covers up all the other emotions going on underneath. Having a good, honest talk to someone you trust can do wonders.

- Find a private space and SCREAM at the top of your lungs.
- Chuck a good ol' fashioned tantrum in your room.
- Do some boxing or just punch a pillow.

Sometimes some basic, primal aggression – not focused at a person, of course – can really help get things out of your system.

- Do some exercise. Pounding the pavement is better than beating up on yourself or someone else.
- Have a nice hot shower and cry, sing or yell while you're in there.
- Write it all down – don't edit it just write it.
- Listen to music that suits your mood.

Remember: Cancer sucks but you are not alone and there are people who will understand and can help.

Unhelpful ways to deal with negative feelings:

Hurting yourself and others – If difficult or painful feelings build up inside you, they need a way to get out and this can lead to harmful or dangerous behaviour. Without the lecture, some things that might seem to help – like using drugs and alcohol, deliberately harming yourself or using violence against other people – are really only ever short-term fixes. They may be tempting ways to cope or escape, but in the long run they can do you and your relationships permanent damage.

Withdrawing – Sometimes when we're angry we try to cut ourselves off from people. It can feel like they're annoying even when they're trying to help, or like they just don't understand. It may seem hard, but try not to push away the people who love you. They only want to help – and it's much harder to go it alone!

getting support

Getting the right sort of support when you're living with cancer is very important. While there may be lots of people looking after the physical side of things, it is just as important to look after the emotional stuff.

Your cancer experience may last for a long time and the kind of support you need may change. Asking for help may be hard – especially if you and others think that you should be “over it” by now.

It may mean having to:

- Admit that you are not doing as well as you would like to be (or are pretending to be). No one is going to judge you on this.
- Open up about what's going on.
- Admit that you don't have all the answers.
- Be honest and let your guard down.
- Not be the perfect patient. Ask for the treatment and information that you need.

But faking the “I'm ok” thing is going to be a whole lot harder.

A good support person will:

- Listen to you.
- Not judge you.
- Be there when you need them.
- Keep things private (if and when you ask).
- Be honest with you.
- Have a sense of humour.
- Not tell you that they know how you feel.

Who can you get support from?

It may take a few shots at finding the right person, but it's worth making the effort.

Parents

- You may find that your mum or dad is able to offer you most of the support you need.
- Remember they have a lot of stuff to deal with, so you might have to spell out for them exactly how they can help you (and when you don't need it!)

Brothers and sisters

- If you have brothers and sisters, they may know you better than anyone else and you may share things with them that you don't with other people. Sometimes it is the unspoken support that is really helpful.
- They can also be useful when you are trying to negotiate with your parents or just don't want to have that awkward conversation.

Other relatives

- Sometimes you get on better with an aunt, uncle or grandparent than you do with your parents – that's totally fine.

Friends

- Some friends may be great at giving you just what you need, but you may need to ask.
- Just being able to express your fears, frustrations and thoughts can help.
- Sometimes all you want is to feel normal again for a while. Be sure to make time to have some fun.

Counsellor

- Seeing a counsellor can be a really good way to deal with your emotions and thoughts.
- Even if you have the support of family and friends, a counsellor will listen to you and you can say things to them that you may not want to say to anyone else.
- The best thing is that you can't hurt their feelings or p*ss them off. They are skilled in helping to work out ways to cope with anger, sadness and fear.
- During and after treatment you should have access to social workers, counsellors or psychologists. Don't be afraid to use them.
- You can also try a school counsellor, the Student Health Unit at uni, the TAFE Counsellor, an Employee Assistance Program at work, or a private counsellor.
- Your doctor can organise a private counsellor (and generally you won't have to pay).

Teachers

- Maybe there is a particular school teacher you have a good relationship with. Teachers work with young people all the time and are often great listeners. Don't be afraid to let them know what is going on.

Remember:
Most young people see a counsellor at some point when they have cancer

“ **One thing I have learnt...**
I found the best information
came from others who had been
through cancer themselves ”

Your local doctor

- Your family GP may have known you and your family for a while, so they might understand what is happening for you.
- Doctors not only treat physical problems, they can help with offering you support. They are often really good at listening and also have medical knowledge.
- You don't need your parent's permission to see a doctor if you are over 14, just your Medicare number (not even the card).

Religious and community leaders

- Priests, elders, pastors, rabbis, monks or other religious and community leaders are experienced in supporting people in their communities. You may already be involved in a youth group. They may be able to give you just what you are looking for.
- Spiritual care can be important for you as you deal with your cancer.

Support groups

- There are organisations that work with young people who are in the same boat and who get what you are going through.
- This might not grab you at first (others have said the same thing) but once you actually go you might change your mind.
- It is said that the best support comes from those who have 'been there and done that'. CanTeen, the organisation for young people living with cancer, has great programs that offer this kind of support (www.canteen.org.au).

On-line support

- There are lots of on-line support groups, blogs and forums for people who have been diagnosed with cancer. One of these is www.nowwhat.org.au.
- It can be helpful to read other people's stories and know that you're not alone in what you are feeling or experiencing.
- Being anonymous and not actually having to talk to anyone may be easier for you.

Religious beliefs and spirituality

Living with cancer can make you start to think about your spiritual beliefs.

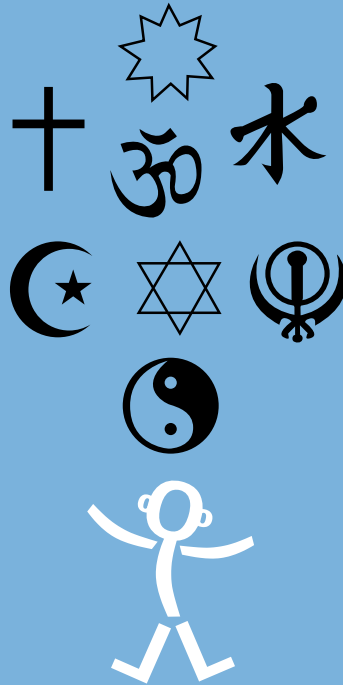
If religion plays a big part in your life then it can provide you with a lot of support and maybe some security as you deal with the experience of having a life-threatening disease.

However, be prepared for your faith to be tested – you may now start to question God or look at your religious beliefs more closely.

It is not uncommon for young people to do this anyway – it's just that this may change the focus or make it more significant.

It might cause some conflicts at home if you no longer want to participate in the customs and rituals of your family's religion.

If you weren't particularly religious before, you might be surprised to find that at some stage you are drawn towards some sort of formal religion. If this gives you support and helps you deal with what is happening for you then it can be a very positive thing.



Belonging to a religious based support group may also help you deal with some of the stuff you are going through.

Even if you are not into traditional religion you might find that you develop an interest in other beliefs and types of spirituality.

Often it's a way to feel like you can get some answers or find some sort of meaning in what is otherwise just a really unfair and tough space to be in.

Not saint

There is a whole lot of stuff out there about how being “touched by cancer” can somehow make you into a saint, cause you to give up all your bad habits and to discover the meaning of life.

It is true that many young people say that the experience has taught them stuff they didn't know, made them appreciate the little things more and helped them find a strength that they didn't know they had.

But for some of you, the expectation that this is how it should be is a really hard thing to live up to.

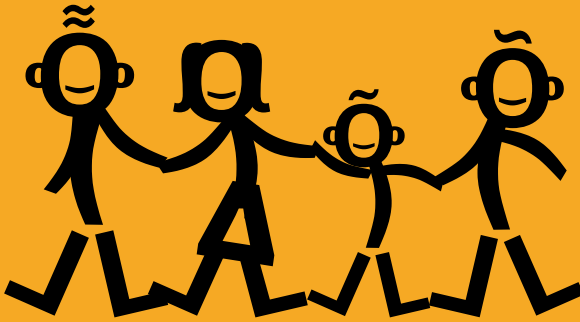
So...

- It's **OK** not to feel special.
- It's **OK** to still get angry with the people you love and not be the perfect son, daughter, brother, sister, friend, boyfriend, girlfriend or partner.
- It's **OK** to not feel really brave and think that the whole experience will be good for you.

- It's **OK** to think the whole thing sucks.
- It's **OK** not to feel positive all the time.
- It's **OK** not to feel “lucky” that your cancer has been cured.
- It's **OK** to come out the other end of this still being the same, faults and all.

Remember:

Everyone deals with things their own way and learns different things from the same experience.



Relationships

Relationships can be tough. Throw cancer into the mix and it can change everything.

Parents, brothers and sisters and friends are all going to be affected by what is happening to you. Everyone will be dealing with their own stuff and there may be big changes in all of these relationships. Dealing with these changes takes patience, honesty and lots of communication – things that are not always easy to find when you are feeling sick, tired and worried.

Cancer may make some of your relationships stronger, may tear some apart or may not change anything. It all depends on the relationship!

Parents

Parents – sometimes they drive you nuts, sometimes they are your best friend. Add the stresses and challenges of cancer and that relationship is really put to the test.

Your cancer diagnosis can be just as overwhelming for your parents as it is for you.

They are dealing with a whole heap of stuff, including:

- Shock, fear, anger and disbelief at your cancer diagnosis.
- Worried about you and the rest of your family.
- Helpless as they can't fix this for you or make it go away.
- Overprotective of you and trying to shield you from the bad news and harsh realities.
- Distracted and not focusing on the normal things.
- Tired, stressed and short-tempered from thinking about everyone else all the time.
- Trying to hide their feelings and put on a brave face for you.
- Worried about medical bills and whether they can get time off work to look after you and your siblings.
- Isolated and lonely. Their friends might not know how to cope and avoid them. They might feel that no-one else understands what they are going through.

It may seem that even when your Mum or Dad are around that their head is some place else. They may be constantly worrying about you and not really focusing on the normal things.

Parents are used to being able to protect their kids and fix things for them. A cancer diagnosis can often make them feel helpless as they have no control over what is happening to you and can't make it go away. This is why they may seem to become overprotective of you and your brothers and sisters.

Helping parents get the balance right

Many parents are so eager to support and protect you that they do not realise that sometimes it feels like they are taking it too far. They want to do everything they can to make things easier for you, but it can feel like they fussing and nagging too much and starting to treat you like a little kid who can't do anything for yourself anymore.

You might really miss your privacy and independence and feel a bit irritated and impatient with your parents.



Talking helps

Sometimes parents need some help to know when to step back. Try to tell them clearly and calmly what you'd like from them – and when you just want to be left alone. Maybe you want to go to appointments by yourself or start managing your medications on your own. You could let them know that the best help they can offer is to just be there for you when you ask, but that you don't always need their attention 24/7.

Some young people with cancer don't want to tell their parents how scared, depressed or stressed they are because they are worried about upsetting them (even more!). But keeping your emotions hidden is probably only going to make you feel more stressed and alone.

It's never too late to start talking to your parents, even if you've never been that close. For some tips on how to start the conversation, check out the "For my parent" and "Just on thing" cards in the back of this book.

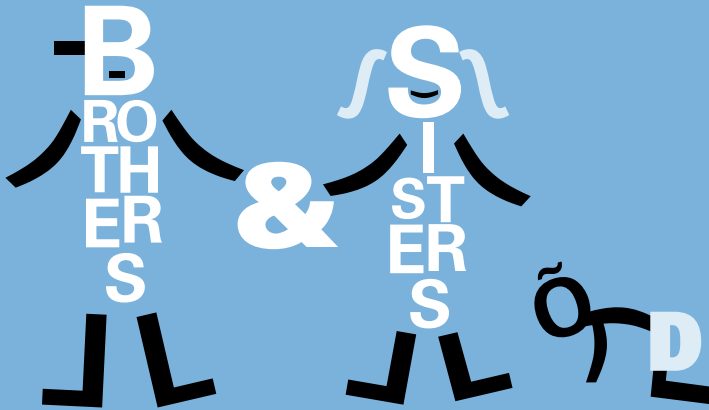
To help your parents understand how you might be feeling and how they can help, you could show them a DVD called 'It's Like This'. This DVD was made by CanTeen and RedKite and you can order it for free from www.nowwhat.org.au.

Many families find that it helps to talk to someone outside the family to get support and information. You, your parents, siblings and friends can all call RedKite for telephone support (1300 722 644) and talk to professional counsellors who know a lot about cancer and the challenges that impact everyone in the family when a young person is diagnosed with cancer.

“

One thing I have learnt is...

... It's never too late to start talking to your parents, even if you've never been that close.



**Best friends or sworn enemies?
Well, probably both actually.
And it can move from one to the other in just a few seconds.**

Being diagnosed with cancer won't make this go away. It's not like somebody waves a magic wand and says "now that cancer is here you will all love each other deeply and never fight".

How you got on before the cancer will have an effect on how you get on now. But in any case, chances are your relationship will change.

You may stop arguing about the small stuff like iPods, clothes and privacy. But you are probably still going to argue about some things – and there is something really healthy about this!

You might find that older siblings become quite protective of you. This can be OK, but it can be really annoying to have another parent. v

Being in hospital for a long time can also impact on your relationship. You might start to feel like you don't have as many things in common any more – like going to school, hanging out and just doing normal day-to-day stuff. Even if you fought and annoyed each other, you might be surprised at how much you miss them.

Siblings can become a really useful link between you and your friends at school, uni and the rest of your world. You might find that your cancer experience actually brings you closer together.

But don't underestimate the impact your diagnosis will have on your siblings. There will naturally be lots of focus on you and your brothers or sisters may start to feel a bit left out and even resentful. This can show itself in various ways like not wanting to visit you in hospital, saying mean things, ignoring you or behaving badly.

We all react differently to difficult situations and express our fears and pain in different ways.

Understanding what is going on inside your sibling's head may help you understand why they behave like they do.

Brothers and sisters might be feeling:**Scared**

Doesn't matter how tough, grown up or brave they seemed, finding out you have cancer can scare the crap out of your brothers and sisters. They're probably frightened about what is going to happen to you and what difference cancer will make to you and the rest of the family.

Sometimes you or your parents may try to protect them and not tell them all of the news about your treatment or prognosis. Not knowing the full story can cause them to imagine the worst, which can be very frightening.

Angry

There will be lots of changes to family life and a lot of attention will be on you. While you are being treated, your brothers and sisters may have to take on extra responsibilities around the house. Your parents aren't home as much and the whole world at home seems like it has been turned upside down.

Your siblings may feel that they are not being treated equally and think that the whole situation is just not fair. They may even be feeling angry at themselves for feeling that way.

Jealous

People will be super nice to you and you may get lots of presents and attention. You may also get out of doing things around the house and get away with being moody or saying nasty things when they can't. This can be quite hard for your brothers and sisters.

Guilty

They may be feeling seriously guilty about your cancer. They feel bad that you got sick and they didn't and that they can still laugh and go out and have fun when you can't. They may feel guilty about complaining about the extra things that they have to do.

They may feel guilty about arguing with you or wishing bad things would happen to you. Or they may feel guilty for not feeling anything at all. They may be in shock or disbelief, or they may just be too busy in their own life. This doesn't mean they don't care; it's just that they need some time to deal with it.

Lonely

Your brother or sister may have to spend time at home on their own or with other family or friends. They may miss you and your parents if you are in hospital for long periods of time and feel left out or neglected. They may also be missing the way things were.

Their friends might not know how to handle the news of your cancer and are staying away from them or don't know how to talk to them about it. They may feel that no-one understands what they are going through and this can be a very lonely experience.

There are ways that you can help your brother or sister understand what you are going through. Just sitting down and talking with them about how you are both feeling is a big first step – but it should help to make things better. You can also get a copy of this book in a version for your sibling called "Now What...? Dealing with your brother or sister's cancer" available on the website www.nowwhat.org.au.

**At the start I
wish I knew...**
that my brother
was just as
scared as me

friends

Your friends are really important – you probably spend as much time with them (or more) as you do with your family.

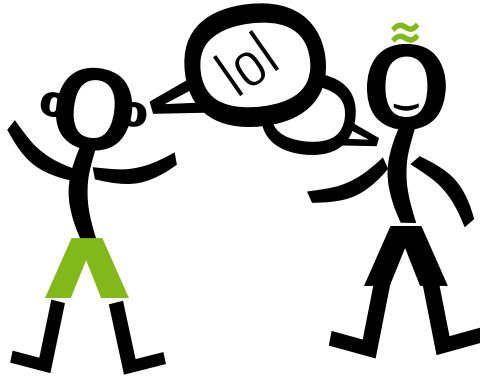
Sometimes friends are amazing and say the right things and are there for you to lean on. But other times when you are living with cancer, friendships get a bit messed up and confused.

There are all sorts of things happening to you that can mess with friendships, like:

- Feeling crappy and irritable while you are being treated.
- Being in hospital a lot.
- Not being able to do the same things as you used to.
- Acting differently because of your cancer.
- Looking different because of treatment.

Sometimes friends can find all of this difficult to deal with.

It might seem like your friends are avoiding you and not calling you or inviting you out anymore. They might not visit you much. They might make insensitive jokes or say



unhelpful things. They might not want to talk about the “C-Word” at all and just pretend that nothing is wrong.

The support of your close friends is probably really important to you and you might feel hurt or disappointed that they are not better at being there for you when you really need their support.

But this is new territory and your friends probably don’t have much experience dealing with someone with a serious illness. If you think about it, before you had this experience you might have acted the same way.

It can help to think of things from their perspective.

Your friends might be thinking:

- What am I supposed to say or do?
- What if I say the wrong thing?
- What can I do to make it better?
- How can I be a friend to someone who has cancer?
- Should I talk about the cancer or will that just make them upset?
- They are always sick and that scares me.

- Should I still share things that are bothering me? They seem unimportant compared to what my friend is going through.
- Maybe they don't want visitors so I won't impose and put them in an awkward situation.
- I don't want to rub it in or make them feel jealous that I am still going out and having fun so I just won't mention it.

As unfair as it may seem, you may have to take the lead and help your friends handle what is happening to you.

Tips to help you stay in touch with your friends.

- Call them, email or invite them over.
- Ask them to keep calling, texting and messaging you and if you don't feel like talking, you just won't respond straight away.
- Ask them to keep inviting you to things and you'll go when you can.
- Let them know that you can talk openly about your cancer.
- Remind your friends that you are still the same person, despite changes in your appearance.
- Tell your friends specific ways they can help – they'll be happy to do whatever they can.

Still talk about normal things. It might really help you stay connected to your normal life.



Things to keep in mind when you are thinking about your friends:

Friends sometimes don't know what to say

Your friends may be scared to say the wrong thing or to ask you a question. Often they will just say nothing. It's not because they don't care, but more that they just don't know what to say. If you want to talk you may have to start the ball rolling.

Friends won't say things to deliberately upset you

Sometimes your friends will say stuff that really annoys you and makes you angry. This can be really hard. But try not to be offended and keep in mind that they didn't try to annoy you on purpose; it's just that they don't understand. It's OK to let them know. You can start with "You know, it bugs me when....".

You will probably be a bit snappy with your friends too sometimes when you're feeling down. That's OK as long as you let them know how much they mean to you once you feel better.

Friends may ask tough or silly questions

Be prepared for questions that may seem strange – remember all the things that you didn't know before you got diagnosed? Sometimes you may not want to answer questions about your cancer. It is alright to let your friends know that you don't feel like talking right now.

Your friends have their own lives

It may seem that your friends are just getting on with their lives without you and you feel a little left out. Try to remember that they have their own lives too and they aren't dealing with the same things as you are. Unfortunately, the world doesn't stop just because you have been diagnosed with cancer (although for you it may seem like you have entered a whole different world).

Stay in touch with your friends

Try to stay in touch and let your friends know that you still want to be part of what's going on even if you can't always go out and do things. It's really important to keep yourself occupied and do some fun things that can take your mind off cancer for a while.

Be as open as you can with your friends. Ignoring their calls and telling them that they wouldn't understand can sometimes work a little too well! Don't be scared that you're going to sound like a whinger. Your friends expect things are hard for you right now.

Friends may change

Having positive people in your life is important at this time. Some of your friends may stay with you and become an amazing source of support, able to listen to your complaints, fears and wishes. These are true friends and you may become very close.

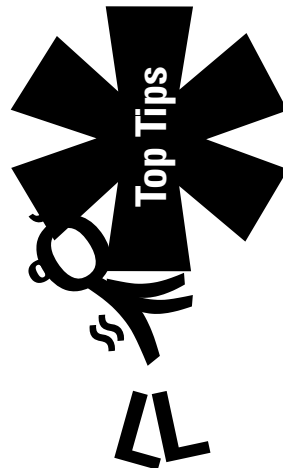
But not all of your friends will be able to handle it and some friendships will fade. Some people will find it hard to understand what you're going through. Some may even bully or exclude you and you may decide that they are just not worth the hassle.

You may also change as cancer can make you have a different perspective on life. You may not relate to your old friends as well and want to find people whose interests are more like yours.

You may form new friendships. It can be really helpful to connect with other young people who are going through a similar thing. They might be easier to talk to about what is happening because they understand. Lots of young people say that this is often the best support.

"Tips for friends" and the "Just one thing" card at the back of this book may be helpful in getting support from your friends.

do
normal
things
with
friends to
give your
mind a
rest





Cancer is a tough topic to talk about (no kidding!!!).

You may have stuff that you want to know but you're not sure how to ask or who to ask. You may have many fears and concerns but don't want to worry or upset people.

While lots of pamphlets and videos show families all sitting around sharing their innermost thoughts, the reality is not all families talk openly and honestly about things that are happening or their feelings. A cancer diagnosis isn't going to miraculously change that. How your family communicates about cancer may depend on how you have always communicated.

It's going to be hard. But the longer you avoid talking about what is really going on, the harder it will be. You've heard it before, but not talking about it won't make it go away.

You shouldn't go through this alone and you may be surprised how much better it is when things are out in the open.

So the trick is to find the right time and the right way for you to talk about stuff.

Things to think about:

- There is no right or wrong way to talk about cancer.
- Let people know that you want to talk about it. People might be avoiding bringing up the cancer because they are afraid of upsetting you.
- It can be difficult to talk if there is a big gap between what you want to talk about and what everyone else wants to talk about.
- It is most important that you talk to people who you trust and feel comfortable with. It is OK if this is someone outside your family.
- Being afraid or scared that you will upset people can often hold you back from talking about how you are really feeling or what is really going on for you.

Tips for talking:

- It may help to think about what you want to ask and what you want to say before you start.
- It may be really hard to start with and there may be lots of silent moments. That's OK.
- Try not to freak out if you or other people get upset – keep going or try again later.
- Talking can be easier if you are doing something else at the same time – like driving in the car or cleaning up in the kitchen – when the focus of attention isn't directly on you.
- Doing something together, like watching a movie or playing a game, can give you a chance to share what's going on when you are relaxed.
- Try not to worry about it too much – this whole thing is strange and scary and it may take time to work out the best way to talk to each other.
- It's OK to still have the odd argument with your parents, siblings, partners and friends. It doesn't make you ungrateful for their support. In fact, it might be nice that things feel like "normal" again.

If talking is too hard

Sometimes talking is too hard but you still want your parents, siblings, partners or friends to know what is happening and how you are feeling.

You could also:

- Write a letter, email or blog
- Find cards and songs that say it for you
- Send an SMS or Facebook message
- Leave signs on your bedroom door
- Draw pictures
- Keep a journal. You can choose to keep it private or share it with your family or friends

If you or your family really has difficulty talking about cancer with each other, it may help to speak to an experienced counsellor or social worker. They can give you ideas on how to communicate with each other or even be there if you need them.

Top Tips

**Talk about it in small pieces,
not all at once**

You've got **WHAT?!** *telling people*

Talking about cancer with your closest friends and family can be challenging enough, but what do you do about telling people in your wider social circle like work mates, uni friends and team mates?

"Will I? Won't I?" Who to tell and what to tell them can be a really difficult area to navigate. You might be unsure of how they will react and afraid that they will treat you differently.

Sometimes your treatment might make it a bit hard not to say something – but how much you tell is still up to you.

There are reasons to tell and not to tell people outside your immediate circle and there will be different things to consider depending on your situation.

Reasons to tell:

- Trying to keep things a secret can take up a lot of energy.
- Your friends and colleagues might feel hurt or left out if you don't tell them about something so serious happening to you.
- Your relationships with other people might become stronger when they know more about you.
- You may need time off study and work to attend treatment. If you tell your teachers and boss the real reason, they are more likely to offer to help you out.
- Your energy and concentration levels might be affected by treatment. It might be better for people to know there is a reason for this instead of them making one up.
- Friends from school, uni/ TAFE and work can help tell others if you don't feel like it. They might be less weird around you if they know what to expect.

Reasons not to tell:

- You worry that people may act weird after you tell them and treat you like you are fragile and vulnerable.
- You feel embarrassed talking about your cancer, as it may relate to private parts of your body (such as your breasts or testicles).
- You can't be bothered telling the same story and answering the same questions over and over.
- You may feel your life is now being dominated by a disease that you didn't ask to have. Maybe work, school, uni or TAFE is one of the only places where you can still be you without being defined by cancer.
- People may want to share their own cancer stories with you – good, bad and ugly – and that can get pretty annoying.

Who do you have to tell?

There are not many people who you really must tell, but letting people know can make things easier for you.

As a student, there is no legal obligation in Australia for you to tell your school about it. But if you think your cancer will affect your marks, it is a good idea to tell your teachers so they help you with your workload or exams if necessary.

If you have a job, you may have to tell your boss, especially if your treatment involves you taking time off. They may also be able to make some special arrangements for you, such as more flexible work hours.

How do you tell people?

You can prepare yourself for telling others about your cancer experience:

- Work out what you are prepared to share and what feels right. Try writing it down first.
- Imagine yourself telling people. Practice saying it in your head.
- Go online and check out some blogs or forums and see how other people do it.
- Give permission to your friends, family or teachers to tell other people if you want them to know, but don't want to tell them yourself. Make sure they understand if you want to keep the information private.
- Be prepared to deal with insensitive or silly questions. Maybe refer people to a website (like www.nowwhat.org.au) to learn more about your particular kind of cancer.
- If you don't know your teachers, lecturers or bosses very well, you may find it easier to call them or write an email or letter.



SCHOOL + STUDY

Bet you never imagined that you would miss going to school?

School makes up a big chunk of your life and it can be scary thinking about what will happen to your studies while you are undergoing treatment.

Many young people who have been through cancer treatment feel it's important to go back to school or study as soon as possible. But if you have been away for a long time it's normal to feel nervous as well as excited about going back to school.

You may feel self-conscious about the changes in your life and unsure how others will deal with them. You may also be worried about catching up on the work, or maybe even having to repeat and being a year behind your friends.

Before you return:

- Get your Mum or Dad to visit or call the school to let them know what to expect and what they can do to help.
- Your teachers might be able to tell everyone at the same time about what's going so everyone knows and won't be so shocked on your first day back.
- Check out if there is someone from the hospital who can visit your school to teach the teachers and students about your cancer. There are also groups who do this all the time, like Camp Quality, who put on plays to teach teenagers about what it's like to live with cancer (see www.campquality.org.au).
- There are organisations that help young people who have missed a lot of school to keep up and prepare to return. One of these is The Ronald McDonald Learning Program. See "Where to get help" for more information.

Friends

Be prepared to notice a change in your classmates' reactions to you when you go back to school. They may not know how to act around you. Try to let them know what you're willing to talk about and if it's OK to ask questions.

On the first day, it might help to have a friend meet you at school to walk in with you so that you are not the centre of attention.

Be prepared for comments and don't be shocked if you hear something dumb being said. People usually tease because they are confused and unsure of how to react around you. And try to remember that it isn't your fault if someone else is teasing you. They are responsible for what they do.

Dealing with looking different

If you're worried about how your friends will react the first time they see you after your treatment, catch up with them before you go back to class. Invite them over or go to the movies so they can get used to the way you look at the moment. It can help to have a few friendly faces when you go back to school or uni (and at least a few less people who might stare!!!)

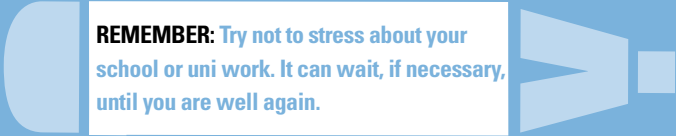
Keeping up

Even if you have gone back to school or uni, you may still miss out on class a lot because you need to go to appointments or have treatment.

You may also still get really tired and not feel 100%. This can make it hard to keep up.

You could:

- Ask a friend to take notes for you if you miss a class.
- Get the teacher to email any work or assignments that you have missed, or they could send the work home with a friend or a sibling for you.
- With your teacher, work out what work is a priority and focus on that – it may be easier than trying to get it all done.



REMEMBER: Try not to stress about your school or uni work. It can wait, if necessary, until you are well again.

Marks

You might feel ready to jump right back into school and make up for lost time. But don't be surprised if you don't find it that easy and your marks aren't what they used to be.

This might be because you were away or lot. Or it might be because some of your treatment has made it harder to concentrate or understand and remember new information (remember: Chemo Brain!). You might feel like you are working harder than you had to before just to keep up. Or maybe your goals have changed.

Your health and getting better is the most important thing at this time, and you and your teachers and parents might have to adjust your expectations for now.

LIVING IN THE

If you live far from the big smoke in Australia, the impacts of cancer can hit you particularly hard.

If you are used to living in the country, having to travel long distances to stay in a hospital in a big town or city might be really stressful.

You may be away from the support and comfort of your family and friends and miss your home, community, lifestyle and the food you usually eat. Being alone in an unfamiliar place is hard and you might feel lonely, frightened or uncomfortable.

There are other challenges too:

Financial issues

Travel costs, petrol, accommodation and eating out a lot can be very expensive.

You or your parents may also have to take time off work or pay for child care. These extra costs might make you feel even more stressed and worried.

But living in the country shouldn't have to impact your treatment decisions and there are many services available in every state that offer assistance for travel and accommodation costs for rural patients.

Missing out on study

If you're away a lot for treatment, you might be able to continue with your regular school work through distance education and doing courses online.



There may also be Hospital School services available in your hospital. You can learn directly from a teacher on the ward or sometimes they can visit you where you are staying in town.

Tips from other rural patients:

- Try to organise several appointments for one trip.
- If you're not feeling well, make sure you take someone with you who can drive.
- Let your support people know that you may not be up for sightseeing or shopping after appointments and that you may just want to head straight home.
- Find ways to stay in touch with family and friends – phone calls, letters, emails, Facebook, MySpace and Skype.
- Make contact with a support group or person near your hospital so you can share your experiences with other people who have been through cancer.
- Find out if there is a Rural Cancer Nurse in your area and/or at the hospital where you are being treated. They can offer advice and help to improve coordination between your rural and metro-based health services.

See "Where to get help" for organisations that offer assistance to rural and regional patients.

Getting back to “NORMAL”



While you were being treated for for cancer, you probably didn't have he time or energy to think about much other than doctors, hospitals, tests and side effects. But when your treatment finally ends...what do you do now?

There is nothing ordinary about returning to ordinary life after cancer treatment. No matter how much you have been looking forward to it, it can still be weird, difficult and scary.

What exactly is a “normal” life now?

You and the people around you have just faced a life-threatening illness and overcome massive challenges. At the risk of stating the obvious, life has seriously changed.

When treatment ends, it might be easier to think about redefining life rather than reconstructing it. By starting a new chapter of your life, you're free to begin again however you want.

Your new kind of “normal” might include changes to the things you do, your plans for the future, your outlook on life and in the things that you consider important.

As you end active treatment, you enter a stage known as “survivorship”.

The transition into survivorship can be both exciting and confusing. Figuring out what to do after cancer treatment is one of the hardest things for a cancer survivor to do. It's important that you give yourself time to adjust.

Keep in mind: Getting over cancer is not as simple as healing the body and getting rid of the disease.

Redefining your life plans

Before you had cancer, you might have been starting to think about the future and decide what you wanted to do with your life. Now that treatment has ended, you may find that while some of your plans and goals can be picked up and still achieved, some others may need a rethink..

- Cancer may have left you with changes to your body, energy levels or emotional state that will prevent you from pursuing your dream job or fulfilling particular ambitions. This can be extremely disappointing and upsetting and will take some time to adjust to. But don't feel rushed or pushed. A time will come when you feel ready to explore new opportunities.
- You may have changed your mind about the career you want. Many survivors find they are inspired by their cancer experience to pursue careers in the health profession or in organisations helping other people who are going through tough times.
- It is also possible that you have no clear idea what you want to do with your life. This is normal too. This is not an easy time of life for many young people and your cancer may not be completely to blame for your confusion and lack of direction.

Take some time to look into different options, write down a list of short-term and long-term plans. Talk to your family, spiritual leaders, career advisors or social workers for advice.

There is no wrong or right way to deal with survivorship – doing what feels right for you is the most important thing.

What does it all mean?

Cancer is a life-changing experience and some young people want to think more about the impact it has had on their life. They want to know and understand WHY it happened to them and what it means that they have survived.

- You may feel that cancer has given you renewed strength and caused you to enjoy and appreciate the smaller things in life more.
- You may also feel that there is no need to search for deeper meaning in your cancer experience. You would rather just accept it and move on and that is OK too.
- You may sometimes feel positively about your cancer experience and sometimes negatively, or both at the same time depending on your mood.
- You may just feel nothing!

Who am I?

As a young person, you are probably just starting to gain a sense of who you are, how you see yourself and how you want others to see you. All of these things together make up your "identity".

Perhaps before cancer, you thought your identity was pretty much decided. Maybe you were the joker, the sporty one or the academic.

Your cancer diagnosis and treatment might have thrown a spanner in the works.

One thing I have learnt is...
... it sometimes takes a while to find the silver lining in the cloud.



- Changes in your appearance and body image may have impacted on your self esteem and confidence.
- Your role in the family, group of friends or romantic relationships might be different.
- You might feel more mature and stronger than before and think different things are important now.
- Even if you feel the same on the inside, people may have started to treat you differently. Many young people find that “cancer” or “being sick” starts to define their identity.

You may also wish that everyone would just treat you like before and not single you out as different. It can help if you spend as much time as possible doing the things you used to do – going to school or work, meeting new people, dating and hanging out with people your own age as much as possible.

Other young people find that they become used to their cancer identity and the kindness and attention they receive. When your treatment ends and the visible effects begin to fade, you may begin to feel invisible and that no one seems to care any more.

After cancer, it can take time to figure out a new identity – and while you’re working on it you might feel lost and confused for a while.

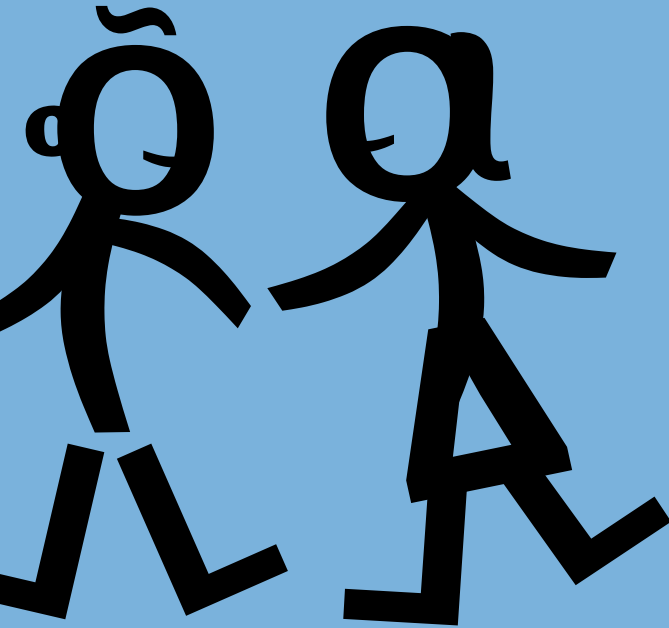
Uncertainty and worry

It is common to worry that your cancer might come back. Although this feeling is normal, it can still be hard to cope with. For some people, the fear is so strong that it might impact your ability to enjoy life, make long-term plans or continue with follow-up treatments.

It can be really exhausting to act as if you are fine all the time. You may have “bad” days when you feel down, sad and alone. Be kind to yourself and try to accept and work through your feelings rather than ignoring them.

You may never completely forget your cancer experience. But it is likely that you will think about your cancer less and less over time.

relationships *after* cancer



Family

Many families expect everything to return to “normal” when your treatment ends. But be prepared – your family may have changed permanently.

Try to be patient with your family as they adjust. It may be hard for them to give you back your independence, or to know how to talk about your cancer.

Spend some time experimenting with new routines and finding out what works for the whole family. Continue to work together and find ways to support each other. You will find a new “normal”.

Friends

You may feel disconnected from your old friends and that you can't relate to them as much any more. Maybe you feel like you have been forced to grow up faster than them and now feel more mature. Or maybe you have missed out on a lot of opportunities to socialise with people your age and you feel like your friends have moved on and left you behind.

As you try to return to "normal" life, you may find that you need to rethink and even end some friendships. This may have happened anyway – cancer or no cancer.

Over time, you will develop your own unique identity and group of friends. Try to be as honest with yourself as you can about what kind of person you want to be and what kind of people you want to be around.

Pressure from others to "get over it"

You, your friends, your family or your employer may expect that life should just return to normal now that cancer is gone from the body. You may hear statements such as "it's time to move on". We know that this just isn't how things work.

When cancer is gone from the body, its repercussions still remain. If you feel like others are pushing you, explain to them that this isn't something that's over for you. It's still there and you need some space and time to cope with it in your own way.

If you feel like you aren't coping, understand that this is OK and get yourself some help.

**Try to
remember**

**You are the expert
on your own life.**

Late EFFECTS

Late what???

“Late effects” refer to health impacts from cancer treatment that don’t occur until years after treatment has finished.

They do not mean that cancer has returned.

Not everyone who has cancer treatment will suffer from long-term or late effects. Even people who had the same type of treatment won’t always suffer the same side effects.

What kind of things are we talking about?

The potential effects depend on many different factors, including what kind of cancer you had, where it was in the body, how it was treated and how old you were.

Late effects could present themselves in any part of the body.

They can include:

- Lung, heart, kidney and liver problems.
- Developing another type of cancer.
- Cataracts (clouding of the lens in the eye, which can cause difficulty with vision).
- Fertility problems.
- Bowel problems.
- Thyroid problems.
- Tooth decay.
- Changes in bone density (osteoporosis).
- Memory and concentration problems.

How will I know?

Medical research is improving all the time and more and more information is becoming available.

Doctors are now able to look at cancer patients’ longer term health.

Regular check ups at the doctor will increase the chances of finding any problems. Discuss with your doctor or oncologist which effects (if any) have been associated with your particular treatment so you know what to look out for.

What causes them?

Cancer treatment may damage healthy cells while it destroys cancer cells. Surgery, radiation therapy, some chemotherapy medications or bone marrow transplantation can stop the growth of rapidly dividing cells in bones, tissues and organs. The damage from these treatments can be mild or serious and the effects may not be seen until months or years after treatment.

Managing late effects

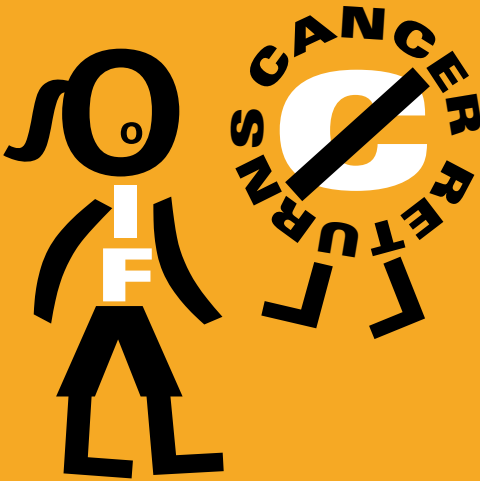
Late effects may be quite hard to deal with, especially after you have made it through all the tough stuff that your cancer has already thrown at you. It might seem like you will never escape from it.

- After finishing treatment, it is helpful to keep a detailed record of your cancer diagnosis, treatments and ongoing plan of care. This will provide other doctors you see in the future with a good knowledge of your cancer.
- Keep your follow-up appointments. Tell your doctor about any symptoms you have. It is always best to have them checked rather than worry.
- Talk to your doctor about whether or not you are at risk of developing late effects from your treatment. In some cases they may be able to tell you what signs and symptoms to look out for.
- Be healthy. We are not certain if we can prevent late effects, but it may still help to stay as healthy as you can. This includes protecting yourself in the sun and avoiding smoking.

Most important – Not everyone will be affected by late effects!



At the start I wish I knew...
that cancer can ***change***
your life



For many of you, living with the worry that your cancer will return can be one of the hardest things.

While the doctors will give you the very best treatment, there is a small chance that cancer will come back. It is important to get as much information as possible and talk over your particular case.

Why does cancer return?

- A returning cancer normally starts with cancer cells that the first treatment didn't fully remove or destroy. This doesn't mean that the treatment you received was wrong or that you have done anything wrong. It simply means that a small number of cancer cells survived the treatment. This is known as relapse.
- It is possible to develop a completely new cancer that has nothing to do with your original cancer. But this doesn't happen very often.

Where does the cancer return?

When cancer comes back, it doesn't always show up in the same part of the body.

Cancer can return in the:

- **Primary site:** When the cancer is in the same place as the original cancer, or very close by.
- **Region of the primary site:** When tumours grow in lymph nodes or tissues near the place of the original cancer.
- **Secondary site or "metastasised":** When the cancer has spread to other areas in the body.

How will I feel?

If your cancer does come back it can feel like the end of the world. The emotions can be powerful and overwhelming. It might feel like all the treatment you have been through has been for nothing. It can be especially challenging if you have been in remission for a long time. ("Remission" means there are no more signs or symptoms of the cancer that can be detected – although there might still be some cancer cells in the body).

It is not uncommon to wonder why this is happening to you and to think that it is really unfair when you have been through enough already.

You may have many of the same emotions that you had when you were first diagnosed – they may even be more intense.

They will probably include:

- **Shock:** Relapse may come as big surprise, especially if you have been feeling well and the tests showed that the cancer was in remission.
- **Anger:** You might feel like you have already been through enough and annoyed at the thought of having to go through it all over again.
- **Sadness:** You may feel really sad about the things you might lose again (and not just your hair). The thought of having to put family and friends through the roller coaster of treatment and its effects can also make you feel sad.
- **Guilty:** You may be very aware of the stress and strain that it puts people under and you may be disappointed in yourself that it has to happen again. Don't feel this way! None of this is your fault, and your family and friends love you and will support you whatever happens.
- **Scared:** This time you know what treatments are like and how things felt. You may also be scared that they can't treat the cancer and that your options are more limited.

But remember! You have something now that you didn't have before: experience.

Treatment options

There are constant developments in cancer research into both treatments and the handling of side effects of treatment. Things may have changed since you were first diagnosed.

What sort of treatment you are offered will depend on what treatment you have had already as well as what type of cancer you have relapsed with and where.

Just like when you were first diagnosed, the doctors and the rest of your medical team will talk you through the options that you have. It is important to get all the information so that you can make the decisions that are right for you.

There may be other things to consider when making decisions about what sort of treatment you have including:

- What impact will it have on your quality of life?
- What side effects – both long and short-term – will you get?
- What are you prepared to go through again?
- Your prognosis – which explains the likely course and outcome of the cancer.

Can I refuse treatment?

If you are under 16, your parents will have a big influence over your treatment decisions.

This may need lots of open communication and negotiations – particularly if you and your parents (and/or your partner) have different ideas.

It is important that you feel OK with the decisions that you make.

Like all the other stages you have been through with cancer, getting the right information and the right support is really important.

Ask people to be honest with you about what is happening.



if treatment doesn't work

Sometimes, no matter what type of cancer you had and what treatments you tried, some people cannot be cured.

Being told that your cancer cannot be cured is probably the hardest thing you and your family will ever have to deal with. This is brutal, unfair and sucks big time.

Learning to live with the knowledge that your cancer is incurable is not easy (and that comes straight from the Department of the Bleeding Obvious) and it will be different for everyone.

There is no right or wrong way to deal with the fact that your cancer cannot be cured and you have the right to deal with it your way.

It is really important to find people who you can trust and who will be honest with you. This may be family or friends but sometimes it may be easier to find someone outside the family.

Making the most of life with a terminal illness often depends a lot on having the symptoms under control. Palliative care is really important to relieve symptoms and treat any physical problems.

If these are under control then you can get on with doing what you want to do.



Emotions

There will be many emotions, some that you might expect and others you don't. At times they can be so strong that they feel like they will overwhelm you.

Denial

This usually means that you continue to believe that your cancer can be cured and that everything will be OK. Denial can be a way to protect yourself from thinking about and dealing with stuff that is just too hard. This is OK, however as your disease progresses, it may get harder to ignore the reality. It can also get in the way of doing and saying the things that you want to do while you are still able.

Anger

There may be lots of anger about what is going to happen and this feeling might not go away. That is OK and normal. You may be angry with yourself because you feel you should have done more to prevent or fight your cancer; or with the

doctors or nurses, for telling you the bad news. You may be angry with fate and feel that it's very unfair that this should happen to you. Finding ways to manage this will help you to focus on the things that are important to you.

Sadness

You may feel heaps of sadness about all the things you won't get to do and the things that your family will miss out on sharing with you.

Frustration

This can come from feeling like you have no control over what is going to happen. However, you can find ways to control some aspects of what is going on, like treatment choices, where you are treated and how you want to spend your time. Not being able to do certain things because of pain and other symptoms could also make you very frustrated.

It is important to make sure that your symptoms are well managed.

Fear

Dying is scary stuff and being really scared is normal. There will be lots of fear – will it hurt, what will happen, where will I die, how long will it take? It's OK to ask people these questions, particularly your doctors. Sometimes they can't give you a specific answer, but it might help to have some information. Having the right information can help you deal with this and stop you freaking out about things –or at least work out what it is that you are most afraid of.

Guilty

Guilt may not be new to you, especially if you have been in treatment for a while. You may feel guilty about how your family is coping, or will cope, and that you are causing them a huge amount of pain. You might also feel guilty because so much time and attention is focussed on you and your needs, particularly if you have other brothers and sisters.

Questions

Getting the right information is so important. It can help you make decisions that are right for you and also help you to understand what is going to happen

Questions you have could include:

- Why did this happen?
- How do you know that there are no more treatments to try?
- Can I get a second opinion?
- How long do I have?
- What will it feel like? Will it hurt?
- Will I be aware of what is happening?

There may be lots of other questions – there is no such thing as a stupid question.

Asking may be really hard, but not asking might be harder.

Finding people who will be honest in their answers might be hard. You could try your doctor, nurses, social workers or a family member.

Things to think about

After finding out that your cancer cannot be cured and after you have dealt with the initial shock and all the other intense emotions, you may start to think about a whole lot of things that you want to do, say, sort out and get in order.

**Ask as many questions as you want
and as often as you want.**



You may want to pack in as much as you can while you can, or you may want to just enjoy the time you have with the people you love.

The important thing is to find ways to communicate what it is that you want.

Some of the things you might want to think about could include:

- Is there something that you have always wanted to do or see?
- Are there things that you want to tell people who you are close to?
- Is there someone you would like to see?
- Are there decisions that you want to make while you are still able to?
- Do you want to plan your funeral?
- Have you talked to your family, siblings and friends about what you want to happen to your possessions, pets and money?
- Have you talked about what your treatment options are as you enter the end stages of life?

If you're able to talk openly about how you feel to your family and close friends they will probably be relieved and able to respond.

You can choose the people that you want to talk to and that you feel will be able to support you. You only need to share as much as you want to share – and at a time when you feel ready.

This is really hard and it will challenge you in so many ways.



Let it all **SINK IN**

Take a step back. Breathe. You've just read a lot and there is so much to take in. Don't worry if you didn't catch it all, you can always come back again later.

We hope this book has given you some directions to help you navigate your way around the weird and scary world of cancer and some confidence that you can get through this!

But there's a lot to learn and think about, so how about we make it as easy for you as possible?

Here's a recap of some of the most important things:

- **You are not alone.** There are many other teenagers and young people who have, or have had cancer, too and are going through some similar stuff to you. You can get in touch with them on websites like www.nowwhat.org.au and in person through organisations like CanTeen. It can feel really supportive to be around people who understand.
- **There are people you can talk to.** Even if your family and friends don't really get what you're going through, there will be people out there who do. Social workers and counsellors are really good at listening and giving you advice. You can talk to them in person or on the phone.
- **Be as open as you can.** You are at the centre of this experience and there are many people nearby who want to help you – including your family, friends and medical team. It's hard to speak up and admit that sometimes you're having a hard time, but telling people how you are feeling and what you want or need can help to make things easier for you.

- **Let your feelings out.** Living with cancer is one of the hardest things you will ever have to do. However you react to it all is normal. It is OK to feel scared, sad, frustrated, jealous and worried. But keeping it all inside or pretending that you are fine doesn't usually help. Try to find the things that make you feel better and be around the people who you trust and feel comfortable with.
- **Things usually get easier with time.** Cancer can make your life really difficult; from side effects and changes to your body, to interrupting school and messing with your relationships and emotions. But over time, you will become used to some of these changes and things may not seem so hard. Try to be patient with yourself and give yourself all the time you need.
- **Everyone's situation is different.** It can be helpful to learn about what sorts of things might happen. But there is no substitute for talking to your doctor about what to expect in your exact case. Everyone's cancer, treatment, prognosis and side effects will be different and it will not help you to compare yourself with other people. The way people react and deal with their feelings is unique too, so let yourself do it in your own way.
- **You can get answers and support.** If you are ever worried, curious or confused about anything at all there are places you can go for more information and advice. Our website, www.nowwhat.org.au is a really good starting point. There are also lots of contacts listed in "Where to get help" of recommended organisations and online services.



never give up hope

Glossary

Glossary: (or what the... does that mean?)

Cancer has a whole language of its own. Some of the terms you may understand, some you may never need to know and some will become part of your everyday language.

Use this list to work out what the medical team is talking about (and to impress your friends).

The underlined words are also defined in the list.

Allogenic: Tissue from a matched donor (often referred to with bone marrow transfusions).

Alopecia: The medical term for hair loss. Alopecia often occurs as a result of chemotherapy.

Anaemia: A condition where there is an insufficient amount of red blood cells in the body. It can cause tiredness and fatigue.

Anaesthetic: A drug given to a patient to stop them feeling pain during a procedure. It can be given as a local anaesthetic to numb the area or as a general anaesthetic to knock the person out!

Analgesic: A drug that relieves pain.

Antibiotics: Drugs used to treat or prevent an infection.

Anti-emetics: Drugs that help control and prevent nausea and vomiting.

Aspiration: Removing fluid from the body with a needle.

Autologous: Tissue from oneself (the opposite of allogenic).

Benign: Non-cancer or non-malignant. Can't spread to other parts of the body.

Bilateral: On both sides.

Biopsy: The removal of a small sample of tissue from the body. This sample is then viewed under a microscope. A biopsy helps doctors to diagnose disease.

Blood: Circulates around the body through arteries and veins. It carries all different substances such as food, oxygen and chemicals to the body's cells, and helps to fight infection. Blood consists of white blood cells, red blood cells and platelets suspended in a liquid called plasma.

Blood count or full blood count (FBC): Different numbers of the types of blood cells in the body.

Blood transfusion: Red blood cells given through the IV. The blood is from another person.

Bone marrow: The soft, spongy area in the middle of bones where red and white blood cells and platelets are made.

Bone Marrow Biopsy: The removal of a small amount of bone marrow, usually from the hip.

Cancer: A general term for a large group of diseases that have uncontrolled growth and spread of abnormal cells.

Carcinoma: Cancer that forms in the tissue at the base of the skin that lines the body's organs.

Catheter: A small tube that can be inserted into the body for removal or injection of fluids.

Central line: A catheter placed into a vein in the chest. It is used to give IV fluids, blood products and take blood counts.

Chemotherapy: The use of special (cytotoxic) drugs to treat cancer by killing cancer cells or slowing the spread of the cells.

Clinical trial: Research that involves giving medications to patients and studying the results. The aim of a clinical trial is to find better ways to treat or prevent disease.

CT scan: A procedure that takes lots of x-rays of the body from all different angles so that a good picture can be formed.

Cytotoxic drugs: Drugs that are given that damage or kill off cancer cells.

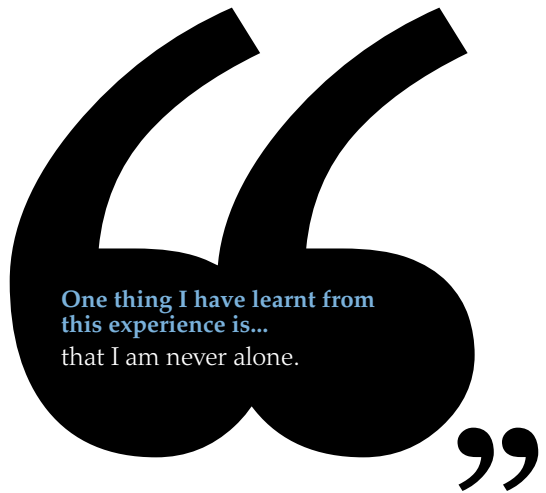
Diagnosis: The identification of a person's disease.

Donor: The person giving their tissue or organ to another person.

External beam irradiation: A common form of radiation treatment.

Fatigue: A feeling of tiredness that isn't fixed by sleep.

Frozen section: A sample of tissue is taken and then frozen quickly so it can be examined immediately under a microscope.



Graft: Healthy tissue is taken from a part of the body or from another healthy person and transplanted to replace diseased or injured tissue.

Haemoglobin: The component of red blood cells that carry oxygen.

Haematology: The type of medicine that studies the blood. The doctor that specialises in this is called a haematologist.

Hormone: A substance made by a gland that helps to regulate reproduction, metabolism and growth.

Immune system: The network of cells and organs that help to defend the body against foreign invaders like germs.

Immuno-compromised: Weakening of the immune system often caused by disease or treatment.

Infusion: Slow injection of a fluid into a vein or tissue.

Intravenous: Giving fluids, drugs or blood directly into a vein.

Limb salvage surgery: When the original bone (or part of the bone) is replaced with an artificial (prosthetic) bone or bone from another part of the body.

Localised cancer: Cancer that has not spread to other parts of the body.

Lymph: A clear fluid that flows through the body carrying cells through the lymphatic system to help fight infection.

Lymph nodes: Small, bean shaped structures that filter the lymph to remove bacteria and other cells, such as cancer cells.

Lymphoedema: The swelling of an arm, leg or other part of the body because of an abnormal build-up of a fluid called lymph in the body tissues. This sometimes happens if the cancer blocks the drainage of fluid through the lymphatic system. It can also occur when the lymph nodes have been removed by surgery or damaged by cancer treatments such as radiotherapy.

Malignant: Cancerous. A malignant tumour is likely to spread to other parts of the body if left untreated.

Metastasis: A secondary tumour that has spread from the primary site through the lymphatic or blood system.

Neutropaenia: An abnormal decrease in the number of neutrophils, a type of white blood cell.

Oedema: Swelling caused by an accumulation of fluid in the body or tissues.

Oncologist: A doctor who specialises in the treatment of cancer.

Palliative Care: Treatment that focuses on relieving the side-effects or symptoms of a disease, but will not cure it.

Plasma: The fluid portion of the blood in which cells and platelets are found.

Platelets: Part of the blood that stops bleeding by aiding blood clotting.

Prosthesis: Artificial replacement for a body part that has been removed. eg. arm, leg, breast.

Radiation: Energy in the form of radio waves that can injure and destroy cells, particularly cancer cells.

Red blood cells: Cells that contain haemoglobin, which carries oxygen around the body.

Relapse: The return of the disease after treatment and a time of improvement.

Remission: The absence of signs and symptoms of active disease.

Staging: A way to identify the extent of disease. It is then used to determine treatment.

Stem cells: Immature cells found in the bone marrow from which blood cells are formed.

Survival rate: The percentage of people who are still alive after a particular length of time with a certain disease.

Terminal: When a disease cannot be cured.

Thrombocytopaenia: A decrease in the number of platelets in the blood, causing blood to take longer to clot.

Total body irradiation: Radiotherapy to the whole body, usually given prior to bone marrow transplants.

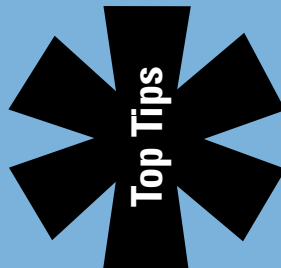
Toxicity: Harmful side effects caused by a drug.

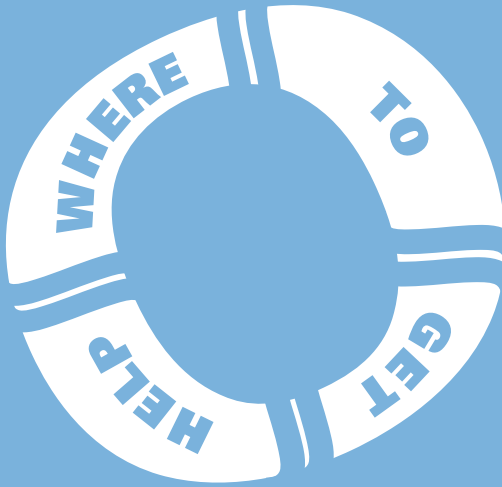
Tumour: An abnormal growth in the body.

Tumour marker: A substance found in the blood produced by a tumour, which can indicate how treatment is working.

White blood cells: Cells in the blood that help to fight infection.

Ask questions even if you are scared to do so





The internet can be a great place to find out more information. Check out these sites to find out more:

Cancer information and support services for young people living with cancer:

www.canteen.org.au

CanTeen is the national Australian organisation for young people (12-24) living with cancer. CanTeen runs programs and activities that connect young people who are going through similar experiences as they face cancer. You can find out how to join and lots more information on living with cancer at this website.

www.nowwhat.org.au

Now What is your space for taking on cancer online. Provides information, practical tips, support and advice across a whole range of areas that impact a young person who is living with cancer.

www.youthcancersearch.org.au

This website is a service directory where young people diagnosed with cancer and their families can find information about services available to them. This includes youth cancer hospital wards,

support organisations, financial services and information services. You can search based on your location and even your type of cancer.

www.cancer.org.au

The Cancer Council website has some really good, clear information on lots of things to do with cancer including different types of cancers, treatments and side effects. From this site you can access the Cancer Councils in your state.

www.redkite.org.au

Redkite provides a range of services to support children and young people with cancer, as well as their families. They provide emotional, financial and educational assistance.

www.campquality.org.au

Camp Quality is the children's family cancer charity that believes in bringing optimism and happiness to the lives of children and families affected by cancer. They provide free recreation programs for children up to the age of 18, and their families.

www.rmhc.org.au

Ronald McDonald House Charities helps to support seriously ill children and families through their many free programs. These include accommodation services for families to stay near hospitals and a learning program that provides tuition and assistance to children who have missed a lot of school.

www.livewire.org.au

The Starlight Foundation's web portal for 10-21 year olds with a serious illness or disability to connect with each other.

www.leukaemia.org.au

The Leukaemia Foundation provides information and practical support for patients and families who are living with leukaemia, lymphomas, myeloma and other blood disorders.

www.planetcancer.com

Planet Cancer is a community of young adults with cancer that provides as much laughter as it does information. Check out the top 10 responses to nosey and annoying questions.

www.teenagecancertrust.org

The Teenage Cancer Trust is a specialist service from the UK for young people diagnosed with cancer. Their website offers information about cancer and its treatment, written specifically for young people.

www.click4tic.org.uk

The Teen Info on Cancer website helps to "understand it, deal with it and share it".

www.preparetolive.org

Aims to be a source of help, hope, information and inspiration for young adult patients, survivors and caregivers coping with cancer worldwide.

www.teenslivingwithcancer.com

Provides answers to questions and information on how to help your family and friends understand cancer. Also has stories and the chance to communicate with people affected by cancer.

www.livestrong.org

This organisation was founded by cyclist Lance Armstrong after his own cancer experience. It has a special Young Adult Alliance dedicated to the issue of young people living with cancer.

www1.petermac.org/ontrac/index.asp

The Victorian Adolescent & Young Adult Cancer Service have developed a website for young people and healthcare professionals and provides up to date information about cancer and current research in the AYA field.

www.2Bme.org

This site looks at the social and physical challenges for young people when they are being treated for cancer.

www.starlight.org.au

The Starlight Foundation aims to brighten the lives of hospitalised and seriously ill children and teenagers in Australia. They offer games, entertainment and fun activities to distract children from their illnesses both inside and outside of hospital.

www.lesssthanfour.org

Less than four is an online community where amputees (people who have lost a limb) can get in touch, ask questions, get answers and support each other.

www.lgfb.org.au

Look Good...Feel Better is a free community service program dedicated to helping women and teenage boys and girls manage the appearance-related side-effects of chemotherapy and radiotherapy. They aim to help you restore your self image by offering workshops throughout Australia on how to enhance your appearance, use beauty products and cope with hair loss and skin changes.

Dealing with grief, loss and feelings

www.kidshelp.com.au

This has a free and confidential online counselling service as well as other helpful information on dealing with tough things.

www.lifeline.org.au

This is a national organisation that has useful information on counselling, health, accommodation and a whole lot of other services. They can help you deal with things like stress, depression and loneliness.

www.youthbeyondblue.com

Beyondblue's website for young people - information on depression, anxiety and how to help a friend. They also provide links to organisations and doctors who have experience dealing with depression.

www.headspace.org.au

Headspace is an Australian site that supports young people with mental health issues – including feeling depressed, tense, angry and worried.

www.skylight.org.nz

A fantastic website with loads of stuff that is helpful and supportive for young people experiencing grief.

Drugs, alcohol, sex and other tricky topics

www.somazone.com.au

Somazone offer free confidential advice and information for young people about things like drugs, sex, mental health, body image and relationships.

www.reachout.com.au

A site specifically designed for young people going through tough times. Reach Out has info on issues like depression, drug and alcohol, relationships, sex and grief.

Information about fertility

www.fertilehope.org

Fertile Hope is a non-profit organisation dedicated to providing reproductive information, support and hope to cancer patients and survivors.

www.thewomens.org.au/fertilityandinfertility

This is the website of the Royal Women's Hospital reproductive health service that has information related to fertility and cancer treatment for both women and men.

Life after cancer - survivorship

www.petermac.org/cancersurvivorship/Survivors

The Adult Cancer Survivorship Centre aims to help improve services and care for cancer survivors in Australia. This website offers lots of practical information and advice.

www.aftercure.org

A US website that provides information for young people who are in remission from cancer.

www.voicesofsurvivors.org

A US website with videos and written stories about what it means to be a cancer survivor. Mostly adult stories.

Support for students

www.uws.edu.au/ndco/getready

The Get Ready for Uni website provides excellent information and advice for students with a disability (which includes living with cancer) who are planning for university.

www.deewr.gov.au/ndco/

National Disability Coordination Officer Program (NDCO) offers information on support, services and resources available for students with disabilities and illnesses at universities and TAFEs in Australia.

Financial assistance

www.centrelink.gov.au

Centrelink is a government agency that offers financial assistance to people in need, including people who are sick, disabled or caring for others. You can also call 13 27 17.

www.cancer.org.au

The Cancer Council can provide details of many local financial assistance services for patients and carers.

www.health.gov.au

The Department of Health can help with financial and practical assistance.

Legal stuff

www.lawstuff.org.au

This website provides lots of information and advice for children and young people about legal matters in a way that is easy to understand.

www.youthlaw.asn.au

Young People's Legal Rights Centre provides free and confidential advice to people up to the age of 25.

Regional and remote patient services

www.ama.com.au/node/4099

The website of the Australian Medical Association provides information on Patient Assisted Travel Schemes available in each state. They help with the cost of travel and accommodation for cancer treatment.

www.vise.org.au

Volunteers for Isolated Students Education provide educational assistance to students in rural Australia and domestic and personal support in the case of illness.

www.angelflight.org.au

Angel Flight is a charity that coordinates free non-emergency flights to medical facilities for people in need.

Palliative care and end-of-life support

www.pallcare.org.au

Palliative Care Australia provides help and information on accessing palliative care.

www.homehospice.com.au

Home hospice provides information and support for people preparing for dying at home.

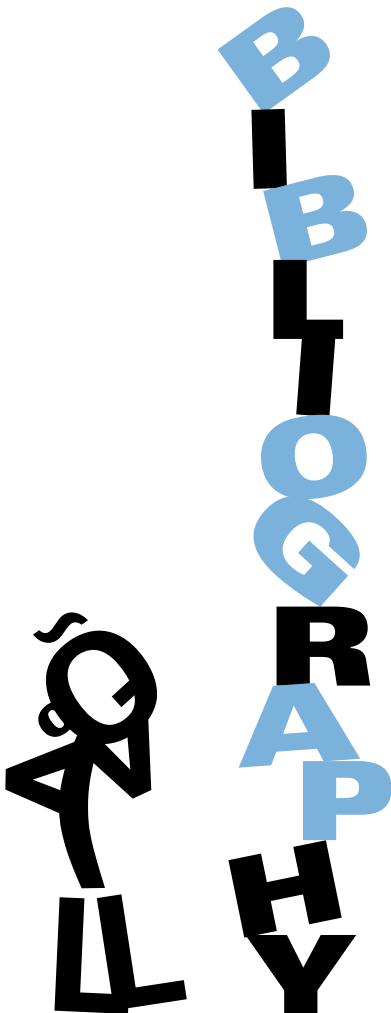
www.makeawish.org.au

Make a Wish Australia makes the wishes come true of children under the age of 18 who have life-threatening medical conditions.

Talk to someone

Kids Helpline	1800 55 1800
Lifeline	13 11 14
Cancer Council Helpline	13 11 20
Redkite Telephone Support	1300 722 644

The following have
been useful in
putting this book
together:



Bullivant, C., O'Brien, T., Anns, M.,
Lean, C., Sinclair, S., Bishop, J. (2009).
*Adolescents, Young Adults and
Cancer in New South Wales*.
Sydney, NSW: Cancer Institute NSW

Cancer Council Victoria (2010).
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Melbourne, VIC:
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Fisher, C., O'Connor, M, Guilfoyle,
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Women And Identity Construction
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Conference, December 2007, Auckland NZ.

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Young People Living with Cancer :
Maidenhead, UK: Open University Press

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Resource for Cancer Survivors.
Austin, Texas: Lance Armstrong Foundation

Macmillan Cancer Support (2009).
*I'm Still Me: a guide for young
people living with cancer*.
London, UK: Macmillan Cancer Support

www.petermac.org/ontrac
onTrac@PeterMac is the Victorian
Adolescent & Young Adult Cancer Service
located at Peter MacCallum Cancer
Centre, East Melbourne.

Recommended reading and resources

Maybe Later Baby: A guide to fertility for young people with cancer

This book provides honest, clear and accurate information so that young people can be informed of their fertility options both before and after treatment, allowing them to make decisions about their fertility at the time that is right for them.

▶ You can order this free book online at www.nowwhat.org.au/resource-order or by calling 1800 669 942.

Now What...? Dealing with your brother or sister's cancer

This book provides support and advice to help young people deal with the practical and emotional challenges of living with a sibling with cancer.

▶ You can order this free book online at www.nowwhat.org.au/resource-order or by calling 1800 669 942.

Now What...? Living with the death of your brother or sister from cancer

This book addresses the issues of bereavement and grief, what it looks like, how it feels and what is normal.

▶ You can order this free book online at www.nowwhat.org.au/resource-order or by calling 1800 669 942.

Now What...? Dealing with your parent's cancer

This book provides support and advice to help young people deal with the practical and emotional challenges of living with a parent with cancer.

▶ You can order this free book online at www.nowwhat.org.au/resource-order or by calling 1800 669 942.

It's Like This...How young people and their parents deal with cancer (DVD)

This DVD is produced for parents of young people to give an understanding of the experience of living with cancer as an adolescent and young adult. It was produced as a joint project between CanTeen and RedKite.

▶ You can order this free book online at www.nowwhat.org.au/resource-order or by calling 1800 669 942.

Cancer Council Booklets

The Cancer Council has a fantastic series of booklets on all types of cancer, treatments and anything else you may need to know. Check out their website for more information. www.cancercouncil.com.au.

Young People Living with Cancer (2007) – Anne Grinyer

This book is the result of research taken to present an account of what it is like to be a young person living with cancer.

Planet Cancer (2010) – Heidi Schultz Adams and Christopher Schultz

This book shares the stories, thoughts and expertise of young adults living with cancer. It presents practical information in a funny, honest and down-to-earth way to help guide you through the world of cancer, from diagnosis to post-treatment.



acknowledgements

Now What – A young person's guide to dealing with cancer.

A resource book for young people diagnosed with cancer.

**Free copies of this book are available by calling 1800 669 942
or by going to the website www.nowwhat.org.au**

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If you would like to support the work of CanTeen call the below number or go to the CanTeen website.



CanTeen Australia

GPO Box 3821, SYDNEY NSW 2000 Freecall:1800 226 833 – www.canteen.org.au ABN: 77 052 040 516

This book is intended as a general introduction to the topic and should not be seen as a substitute for advice from doctors or other health professionals. All care is taken to ensure that the information contained here is accurate at the time of publication.